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ABSTRACT

This volume addresses the needs of decision-makers involved in implementing Public Law 99-457, Part H, which establishes a federal discretionary program to help states plan and implement a comprehensive, coordinated interdisciplinary program of early intervention services for children from birth through age 2. Chapter titles include the following: "P.L. 99-457: A Map for Planning Statewide Early Intervention," "What Children and Families Will Be Served through the System?," "How Will These Children and Families Be Brought into the System?," "What Strengths and Needs Do These Children and Families Have? Evaluation," "How Will the Needs of Children and Families Be Met? Establishing Goals, Identifying a Case Manager, Services, and Financing Services," "What Personnel Will Be Needed to Provide These Resources and Services and How Will They Be Prepared?," and "What Kind of Management and Monitoring Is Needed to See That the Goals of Early Intervention Are Accomplished?" A list of references accompanies each chapter. (JDD)

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Mapping the Future for Children with Special Needs

P.L. 99-457

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Mapping the Future for Children with Special Needs
P.L. 99-457

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It is our pleasure to offer this Early Intervention Consortium Project monograph to the wide variety of people involved in carrying out the new national commitment to services for very young children with special needs and their families. Making a contribution to early intervention efforts is an important part of the Administration on Developmental Disabilities (ADD) mission to encourage the independence, productivity and community integration of people with developmental disabilities. The University Affiliated Program network which, along with Protection and Advocacy and State Planning Councils, is a major component of the ADD program, was an excellent resource for developing this project. For the past twenty-five years, the UAPs have contributed exemplary clinical services, research, training and information dissemination activities with a strong emphasis on the interdisciplinary approach especially important with services to very young children. We are hopeful that this monograph will be of genuine assistance in the important tasks ahead.

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Introduction

This publication developed by the American Association of University Affiliated Programs (AAUAP) Early Intervention Consortium project is intended to address the needs of decision-makers involved in implementing P.L. 99-457, Part H, by providing a practical outline for decisions that need to be made related to the law, and providing material on issues of specific decision-making concern, including the populations to be served, childfind efforts, family evaluations, services, funding, training and administrative issues.

Public Law 99-457, the Education of Handicapped Act Amendments of 1986, serves as a symbol of the great progress that has been made to date in understanding the early development of children with disabilities and how to influence that development positively. The law is also an outline of the task of translating what has been learned into services that can be shared broadly with those children and families in need. In addition, the law supports the continuance of the process of learning about what is most effective in promoting the development of the very young child with disabilities.

Part H of the law establishes a new federal discretionary program to help states plan and implement a comprehensive, coordinated interdisciplinary program of early intervention services for children from birth through age 2. Before the passage of this bill, only a handful of states had mandatory services for children with disabilities from birth. Timelines on the implementation of an entire new system of early intervention services will be challenging in the extreme, but it will be of great importance that the information gathering and planning stages of implementation not be neglected.

Involvement of ADD

While P.L. 99-457 is an amended education bill, it has a new and heartening focus on interagency cooperation in carrying out services for children with special needs. In ADD's own reauthorization legislation, P.L. 100-146 The Developmental Disabilities Assistance and Bill of Rights Act, many areas that related directly to P.L. 99-457 have been strengthened. P.L. 100-146 includes early intervention as one of its priority funding areas. Case management, which plays a major role in the implementation of P.L. 99-457 services, is also a priority area of ADD funding. There is an emphasis on supporting the role of the family in assisting persons with developmental disabilities, on interagency cooperative efforts and a continued emphasis on interdisciplinary training efforts which will be a major component of state early intervention personnel development plans.

As an expression of these common themes, ADD funded the Early Intervention Consortium Project in July of 1987 through its University Affiliated Program component. The UAP component of the ADD efforts had its origins some 25 years ago and now is a network of some 49 programs at 55 sites. Thirty-five of these programs are funded through ADD, 7 are ADD satellite programs and 21 receive Bureau of Maternal and Child Health and Resources Development training funds. Together, they share an ongoing commitment to increasing the productivity, independence and community integration of people with disabilities through interdisciplinary training, exemplary services, technical assistance and dissemination of information.

Serving the needs of the very young child with special needs has been a focus of UAP efforts since the beginning. The Early Intervention Consortium included four University Affiliated Programs with special interest and expertise in early intervention: The University of Iowa, Utah State University, the University of Washington and the University of Wisconsin-Madison.

The specific contributions from the consortium project members were organized around the basic questions that those involved in planning the implementation of P.L. 99-457 will have to ask:

- What children and families will be served through the system?
- How will these children and families be reached by the system?
- What strengths and needs do these children and families have?
- What resources and services will help these children and families meet their needs?
- What personnel are needed to provide these resources and services and how will they be prepared?
- What kind of management and monitoring is needed to see that the goals of early intervention are accomplished?

We have outlined some of the major issues that will have to be considered in answering these questions for each state, and provide examples of how the question has been answered in some programs as well as resources for finding out more about the issues.

The materials have been targeted specifically for a meeting in July of 1988 planned by the Federal Interagency Coordinating Council, which will be attended by many people involved directly in the implementation process. We hope that, in addition to its use for that group, it will become part of the growing body of resources that states can use in implementing this important system of resources.

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CHAPTER 1

P.L. 99-457: A Map for Planning Statewide Early Intervention

Jack and Helen and their two children might be a national "classic," a family that symbolizes both the productivity and rewards of American life. Both work in jobs that are meaningful to them, not just a way to make a living. They have a strong relationship with each other, solid ambitions for their children, good friends and family relationships, and the time and money for fun. They have what we might want for ourselves, and what we would not begrudge others. With the birth of a third child with serious disabilities, their life is suddenly changed. The trauma, the change in control, drastically alters the picture they have of themselves and of their life together. They are a family in crisis.

Like Jack and Helen, Joan wants to be productive, to be happy, to have control over her life. Joan is fifteen years old, living in a chaotic family and in poverty. She is a high school drop out, single and now a mother. Her new son Peter was born prematurely with serious health problems, and now already has signs of significant developmental delay. We know that Peter, with his double risks of biology and environment, is among our most vulnerable and powerless citizens. We know already that his chances for becoming a competent and productive adult are compromised.

Both families, and thousands of variations on them, are the focus of Part H of Public Law 99-457 which establishes for the first time a national policy to support very young children with disabilities and their families, acknowledging the long-term benefits support offers to both the child's development and the overall strength of the family. The legislation promotes services that can reach a range of families, from those with many resources who are thrown into crisis with the arrival of a special needs child, to those families who are vulnerable or in crisis even before a child with disabilities is added to their lives. The law does not establish specific services, but a statewide system of early intervention services. The system is carried out through the fourteen minimum components that must be put in place. These components introduce some new elements to services, such as the Individualized Family Service Plan (IFSP) and the Interagency Coordinating Councils (ICC's) which are central to both the family-centered nature of the bill and its emphasis on interagency collaboration.

Who will touch these families? Who can offer help and at the same time help build confidence and resources within the family members? The value of services called for in this ambitious legislation will ultimately be determined by the wide variety of "hands on" early childhood educators, therapists, social workers, physicians, nurses, psychologists and others who will work with families in the practice of early intervention.

What do these people need to do their job well? What kind of administration, what kind of standards, rules and regulations will enhance, rather than inhibit, their ability to work collaboratively with children and families? What funding structures will allow them to respond most flexibly? What kind of training will they need? These are the questions that must be answered as state coordinating councils and lead agencies respond to the law's requirements. Technical assistance and information developed for these groups must offer concrete information and ideas that have *worked*, that have enhanced the ability of families and practitioners to respond effectively to the needs of children.

The Evolution of Services

Services to infants with disabilities were first based on rehabilitative principles that emphasized the development of functional and cognitive skills in the child. This service delivery system focused on direct intervention with the child. The family was not seen as having the skills necessary to take part in this change effort. Minimal interactions or "interfaces" existed between the system and the family.

Only later, in the mid to late 1960's did concern for the development of the whole child become the focus of services for young children with disabilities. The interaction between child and caregiver was recognized as the single most powerful force for enhancing the child's development. The interaction between the interventionists and parents was then seen as a critical part of early intervention.

Professional "interventionists" working with infants and toddlers with disabilities were using modalities of therapy and educational techniques that had been developed for older children and were being adapted for services to the younger child. There were few, if any, guidelines or models for use with very young children nor were there federal or state regulations for implementing services that experience had shown were appropriate. Through the 1970's and 80's, building on contemporary developmental theories and new experiences in practice, parents, family advocates, and concerned professionals initiated studies, developed model programs for infants with disabilities and their families and ultimately formulated practice into legislation. This legislation, the 1986 Amendments to the Education of the Handicapped Act, P.L. 99-457, Part H, calls for evaluation, planning and implementation activities to encourage the development of the child and support the family unit.

The Responsibilities of Implementing Agencies

P.L. 99-457 required federal enabling regulations to structure its implementation in a uniform manner throughout the nation, but it left considerable room for state and trust territories to determine the parameters of implementation. The original area of interaction between the interventionist and the child or child/family unit is preserved. But P.L. 99-457, Part H, created additional interactions between the federal government, state governments, and local agencies to carry out four distinct phases: 1) planning, 2) oversight, 3) resource allocation, and 4) implementation at the interventionists' level.

Agencies involved include the federal Office of Special Education and Rehabilitative Services; Office of Special Education Programs; state lead agencies and interagency coordinating councils; and local educational agencies. Through additional legislation and federal letters of understanding and agreement, other federal and state agencies have general and/or specific roles and responsibilities. These include, among others, the Administration on Developmental Disabilities; the Bureau of Maternal and Child Health Services and Resources Development; and the Administration on Children, Youth and Families, including Head Start and Child Protection Services.

All participant agencies must be aware that through the policies, procedures, rules, and coordinating agreements they create, they can enhance or inhibit the ability of families and direct care personnel to work together effectively.

Key Components

Each of the 14 minimum requirements of the legislation must be analyzed to permit the implementing agencies complete understanding of its purpose. The agencies must also understand the potential impact of their decisions regarding each component on the interaction between the interventionist and the child/family unit. These components are:

Basic Elements of Part H, P.L. 99-457

1. **Definition of developmental delay.**
2. **Timetable for availability of services.**
3. **Comprehensive multidisciplinary evaluation of needs of children and families.**
4. **Individualized family service plan which includes case management services.**
5. **A comprehensive child-find and referral system.**
6. **Public awareness program to focus on early identification.**
7. **A central directory of services, resources, state experts, research and demonstration projects.**
8. **A comprehensive system of personnel development.**
9. **A single line of authority to a lead agency.**
10. **A policy for contracting or making arrangements with local service providers.**
11. **A procedure for timely reimbursement of funds.**
12. **Procedural safeguards.**
13. **Policies and procedures for personnel standards.**
14. **A system for compiling data regarding the early intervention program.**

While these 14 requirements present the skeleton of a complex process of implementation, to respond to them states will have to answer a series of basic "systems" questions regarding early intervention. These questions include:

- **What children and families will be served through this system?**
- **How will these children and families be reached by the system?**
- **What needs and strengths do these children and families have?**
- **What resources and services will help meet the needs of these children and families?**
- **What personnel will be needed to provide these resources and services and how will they be prepared?**
- **How can the system be managed and monitored to see that the goals of early intervention are accomplished?**

In Figure 1-1, these questions are set in the context of the 14 components that are required under the law, with the understanding that in reality there are complex overlaps between requirements. The figure gives space for information that would be part of the decision-making process: identifying options and resources available, and evaluating and choosing options that best fit the needs and resources in each state. The figure then marks out space where the roles of various people involved in decision-making and implementation might be described.

It is particularly important that the roles and responsibilities in decision making, and in carrying out the decisions, be considered broadly. If the goal of enhancing the central relationship between families and direct care personnel is to be achieved, and if the interdisciplinary and interagency involvement critical to the implementation process is to be achieved, the broadest base of involvement, the most democratic involvement, must be encouraged from the beginning. It should be a participatory philosophy that should guide decision-making.

The job of the interagency coordinating committees and others involved in state level planning is to find a way to fill in the blanks in Figure 1-1. What are the specific decisions that need to be made about defining developmental delay? What information would help with these decisions? How will parents and direct care staff take part in these decisions?

Figure 1.1

Map for Planning Statewide Early Intervention

STATEWIDE EI PROGRAM	PL 99-457 "THE LAW"	DECISION-MAKING PROCESS			
SYSTEMS QUESTIONS	MINIMUM REQUIREMENTS	IDENTIFICATION OF OPTIONS	EXAMPLES OF EXISTING PRACTICES	EVALUATE OPTIONS	SELECTION OF OPTION
What children and families will be served through the system?	Definition of developmental delay (1)				
How will these children and families be brought into the system?	Child find (5)				
	Public awareness efforts (6)				
What needs and strengths do these children and families have?	Evaluation component (3) IFSP (4)				
What resources and services can help meet the needs?	IFSP (4)				
	Statewide directory (7)				
	Timetable for services (2)				
	Contracts with service providers (10)				
	Coordination of resources (9b)				
	Assignment of financial responsibility; timely reimbursement (9C) (11)				
	Interagency agreements (9f)				
What personnel should provide these resources and services?	Policies, procedures related to standards for personnel (13)				
How will personnel be prepared?	Comprehensive system of personnel development (8)				
What kind of management and monitoring is needed to see that the goals of early intervention are accomplished?	Single line of responsibility to lead agency (9)				
	Administration and supervision (9a)				
	Insurance of service provision pending resolution disputes (9d)				
	Resolution of inter- and intra-agency disputes (9e) Formal interagency agreements defining responsibility (9f) Procedural safeguards (12) System of compiling data on EI programs (14)				

EXAMPLES OF DECISION-MAKING PARTICIPANTS AND THEIR ROLES

FAMILIES	DIRECT CARE PERSONNEL	COMMUNITY ADMINISTRATORS/ SUPERVISORS	COMMUNITY/ STATE INTERAGENCY WORK GROUPS	LEAD/ COOPERATING AGENCIES	INTERAGENCY COORDINATING COUNCIL	FEDERAL AGENCIES	FEDERAL LEGISLATORS

The purpose of this monograph is to choose some of the areas from Figure 1.1 that have seemed of particular concern to decision-makers and to help fill in background and options available.

- **What children and families will be served through this system?**
    - Definition of developmental delay
    - Issues of including at-risk populations
- **How will these children and families be reached by the system?**
    - Child Find
    - Public awareness efforts
- **What needs and strengths do these children and families have?**
    - Issues surrounding the IFSP
    - Evaluation
- **What resources and services can help meet the needs of these children and families?**
    - IFSP
    - Service Options
    - Financing Issues
- **What personnel will be needed to provide these resources and services and how will they be prepared?**
    - Shortages
    - Standards and certification issues
    - Personnel preparation issues
- **How can the system be managed and monitored to insure that the goals of early intervention are being accomplished?**
    - Lead agency
    - Participation in implementation
    - Interagency issues
    - Due process
    - Balancing the priorities

Under each topic we have tried to provide resources in the form of program examples, written material and or technical assistance contacts. Our focus is on Part H of the legislation rather than 619 which strengthens the preschool component of P.L. 94-142. However, in areas such as financing and personnel preparation, issues for both populations will be covered.

While there are still many unknowns in this legislation, the implementation has already begun. We hope that these materials will offer both a framework and specific information to help with that process.

CHAPTER 2

What children and families will be served through the system?

The purpose of Public Law 99:457 Part H is to support the development of a system within each state that will provide services to very young children with special developmental needs. The law calls for two major decisions related to defining the population of children to be served. One is for a definition of developmental delay that will be used in determining eligibility for services. The second is the option provided in the law for expanding eligibility criteria to serve children from risk categories. While there are a number of different approaches to categorizing vulnerabilities in very young children, most will be covered in these four major categories:

> **Established Risk or Disability.** These are children with identified conditions or disabilities that we know can adversely affect development. Cerebral palsy, spina bifida along with many other diagnoses would fall into this category.
>
> **Developmental Delay.** These are children with or without an established diagnosis who by assessment measurements have fallen significantly behind developmental norms. It is the *degree of delay required for service eligibility* that must be decided.
>
> **Biological Risk.** These are young children who do not have an identified disability or delay, but who, because of biological circumstances, such as very low birthweight or prematurity, have a higher than normal chance of developmental problems.
>
> **Environmental Risk.** These are children without identifiable biological risk factors whose development is seen as vulnerable because of environmental conditions. Drug or alcohol abuse in parents, teenage parents, mental illness in parents and poverty are all factors in a child's environment associated with a higher than normal appearance of developmental problems.

The choice of which children and families to serve under the system developed under P.L. 99-457 will require consideration of a number of important parameters.

Wide or Small Net: Numbers and Costs

In considering the categories of disability, delay, and risk to use in defining eligibility, the overall decision relates to whether to cast a wide net or a narrow one: whether to bear the expense of broad inclusion and providing services to children who may not greatly benefit from them, or casting a narrow net with more stringent criteria and missing some children who could have benefited from services.

The criteria for inclusion in the system will determine how many children will be in it. A liberal definition of developmental delay, for example, using only one standard deviation below the mean for one of five developmental areas would yield a vastly different population from a system that required such a deviation in two or three areas. Depending on these choices service might range from 1% to 20% of the population of children in the 0-2 age group.

Under the law, all children who meet the eligibility criteria must be provided with services. Since states have a great deal of discretion about the eligibility criteria, it is possible to restrict the number of children served by manipulating the eligibility criteria. The funding authorizations in P.L. 99-457 were based in part on estimates by the Congressional Budget Office (CBO) and the Congressional Research Service (CRS) on the number of children to be served. For example, the CRS applied findings from various studies and estimated that the number of 0-to 2-year-old children in need of early intervention services would be about 320,000, and CBO estimated that about 333,000 three- to five-year-old children would need services, of which about 70,000 were presently unserved.

There is some information which suggests that both of these estimates were substantially low. According to Fox and Yoshpe, (1987, p. ii) estimates developed by the first 15 states who indicated they would apply for Part H grants show the number of eligible infants and toddlers would be closer to 526,000 instead of the 320,000 estimated by CRS. If the number of children needing services is larger than estimated by congress, then the amount of money available to provide services to each child will be lower than estimated and states would have to fund a greater proportion of the total cost of early intervention.

The relationship between setting eligibility criteria at different levels and the financing of early intervention programs is unfortunately very real, since Part H funds are based on the census of 0 to 2-year-olds. If only the most severely disabled children are served, then more money will be available to provide services to each child. On the other hand, it may be that a much smaller amount of money can be spent on children with mild disabilities or at-risk children to produce the same or larger gains.

But early intervention costs cannot be analyzed like the costs of producing washing machines. Deciding on the cheapest way to produce washing machines would be a relatively clear-cut decision. Deciding what a particular gain in developmental functioning is worth for a child with severe disabilities versus an at-risk child is a value judgment of a highly complex nature.

Decisions about eligibility will dramatically influence the amount of money available for each child, and consequently the types of services that can be offered. These decisions will also be influenced by how we define "service" and by our knowledge of the effectiveness of services, both issues discussed in Chapter 6. Making these decisions will require wisdom, not an analysis of cost-benefit ratios.

The most inclusive criteria possible is what would most be in the spirit of the law. It is not the case that the child with the clearest disability or delay is the most seriously vulnerable. The issue is summarized as by Jack Shonkoff:

> "If we were to look at this question from a public policy point of view and decide that we really want to target our resources on that part of the population that is most likely to have the greatest problems later, it's very possible that some children considered at risk represent a more vulnerable group than some children with identified disabilities. Certainly children with specifically diagnosed disabilities need early intervention services and will continue to need help later on. However, it doesn't necessarily follow that the most vulnerable population are children with identified disabilities. In fact, establishing a cutoff based solely on diagnosis means that we may actually exclude some who are more likely to have problems" (Weiner and Koppelman, 1987).

Flexibility Versus Standardization

Another important parameter to consider is the degree of flexibility and individual decision-making that will be left to the parents, professionals, and paraprofessionals involved in determining eligibility. Flexible eligibility criteria will leave much of the decisions regarding eligibility at the local level. Although professionals are expected to be fair and objective in their decision-making, they also can make decisions based on personal biases, making services available in an uneven way. On the other hand rigid procedures that will guarantee more uniformity may prevent professionals from using their best judgment regarding specific child and family needs, and prevent the concerns of parents from carrying much weight. Children with multiple disabilities who do not fit neatly into one or another approved diagnostic category may be denied entrance. The parent or experienced professional who observes subtle problems in a child which do not yet show up on assessments will not be able to access preventive services.

Parent concerns should be considered seriously in establishing eligibility . One parent sees an important point in making *some* kind of services available just on the basis of parent concern. "A child is taken maybe one time to the local physician's office and the mother is saying, 'He is just not acting right, he's just kind of lazy or he just doesn't seem to move around much,' and the doctor is saying, 'Oh you know he'll grow out of it' or 'It's just a stage or something.' He's not able to see that regular daily kind of thing that the mother is seeing. I think if parents feel there may be a problem, if there is a mindset that there is, that a child is different, then they should be receiving services. Not necessarily their *child*, but that *family* should be receiving services. A service because they are concerned---they should be eligible for some relief and assurance."

The balance between local norms and state or federal regulations are also part of this issue. Meisels (1984) supports the concept of local norms. Sensitivity to various community and cultural perceptions of infant and toddler development is important. On the other hand, parents across the country have expressed concerns about the discrepancies in services between states, and a desire for consistent definitions so that mobility and career choices are not limited by service availability.

Formal Assessment Instruments Versus Danger of Labeling

The criteria for eligibility should also consider whatever stigma might be entailed for families in having a child receive or need a label before receiving services, even if that label is "delayed" rather than a specific diagnosis. What those labels are and how they are perceived by families should be an important consideration.

"There has to be some way to make doctors unafraid to send a child on at two or three months that is not doing something," reports a father of a child with disabilities. "All he has is worried parents saying, 'But gosh, in the book it says this child should be rolling over.' There has to be some way for that doctor to legitimately say, 'Okay it's time now. Go to this place and see if there is anything wrong.' But at this point the way I understand it, they can't do that without some documentation. They have to have a reason for sending that child some place. So there has to be X amount of time lost before there's a diagnosis, before there is eligibility. I'm very concerned in my daughter's case, with the labeling being put on at the age of seven months. She was labeled with a mental disability at seven months. Never should of happened. Perhaps a number system rather than words. You know, this child needs 4 for physical development, but only a 2 on speech. Label the service, not the child."

Examples of Existing Practices

Among states that had services to birth before the passage of P.L. 99-457, assessment-based determination of eligibility was used. Assessment-based criteria present multiple problems, most significantly by precluding the provision of services to children who are currently demonstrating mild developmental concerns which might respond to preventive interventions before they would be eligible as developmentally delayed.

Mississippi, North Carolina and Louisiana which have not previously had mandated services to birth, have proposed eligibility requirements which address the inherent problems in the use of assessment instruments in the first year of life.

The southern states as a whole represent the greatest number of younger children who might be considered at risk for environmental reasons. Families living below the poverty level and teen parents are overrepresented. Robert Campbell, Director of the Mississippi University Affiliated Program at the University of Southern Mississippi estimates that as many as half of the state's newborns could be eligible for services if all environmentally at-risk infants were included under Part H.

Mississippi's proposed response is to provide tracking and case management services to infants in multirisk social environments with three or more of the following factors.

- mother under age 15
- family history of abuse and neglect
- parental psychiatric history
- maternal history of developmental disabilities
- aberrant patterns of interaction and/or no attachment
- lack of support and resources (to be defined)
- low educational level of mother (to be defined)

In Louisiana, the proposal for determination of an infant who is at risk is dependent upon a physician's documentation. At twelve months, infants served under the at-risk category must undergo a multidisciplinary evaluation and meet more specific, assessment based eligibility criteria in order to continue receiving services.

North Carolina, following the lead from **Warning Signals** (Blackman, 1986) has recommended the inclusion of at-risk infants and toddlers through the identification of children who demonstrate atypical development but who do not meet specific eligibility criteria for the category of developmental delay. Such an approach permits preventive intervention services to be provided on a short term basis until the infant or toddler no longer requires early intervention or becomes eligible under the specific definition of developmental delay. This approach recognizes the dynamic state of eligibility. The rapid growth and development which occurs during the first years of life often makes infants and toddlers difficult to diagnostically categorize.

SUMMARY

Deciding what eligibility criteria can reach those children and families who can benefit from services, and assessing the services and financial resources that might be available for them is a first step. The next step is to develop public awareness about the availability of early intervention and a "user-friendly" approach to bringing potentially eligible children and families in touch with the service system.

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CHAPTER 3

How will these children and families be brought into the system?

Defining those children and families who will be served is the first step in implementing the mandate of P.L. 99-457. But it is clear that without adequate public awareness of early intervention and an appropriate process leading from child find efforts to actual services, many children in need will never be identified.

There are basically two objectives for child find activities: 1) to identify currently children eligible for services and 2) to identify potential enrollees in services, children whose risk situations warrant ongoing monitoring for future service needs.

But child find activities can also be structured as preventive efforts, in line with the three types of prevention described in public health efforts.

Primary prevention includes efforts that are actually designed to prevent a disability or disease. Public awareness efforts in early intervention can be structured to tie in with state level programs to encourage childhood immunizations, safety programs and efforts to reduce rates of premature births through pregnancy education.

Secondary prevention involves efforts to identify children who have presymptomatic or subclinical situations that can become disabling unless intervention is provided. Examples of secondary prevention efforts include newborn metabolic screening to identify such conditions as PKU or congenital hypothyroidism in which major consequences can be prevented through treatment.

Tertiary prevention includes activities or interventions that follow the actual diagnosis of disease, disability or delay which are designed to reverse, arrest or limit the effect of a disability.

The way each state defines the population to be served will influence the "preventive" efforts that tie in with early intervention services. It is important that the early intervention system be seen as part of a continuum that includes these three prevention areas.

There are two main spheres of activity for child find. The first is public awareness: Letting the right people--people who might need early services or refer other to them--know about early intervention services, their purpose and effectiveness and about the availability of specific child find measures. The second includes the actual screenings and other activities. These activities which can help find children eligible for services include:

- Hospital based screenings and follow-up programs
- Ongoing screening and referral systems
- Tracking systems
- Registries

No perfect system for identifying infants who have, or may be at-risk for having, disabilities exists. The great majority of infants to be served under P.L. 99-457 will not be identified at the time of birth, but will become eligible during infancy or the toddler years. A comprehensive child find system must include identification strategies that span the range from birth through the first two years and link with child find activities under Part B, the preschool portion of the law.

There is a wide variety of specific program options to chose, adapt or create to carry out the "comprehensive child find" requirement of Part H. Some basic issues will need to be resolved by decision makers in developing a child find process that is most effective in responding to individual state and trust territory needs. Many issues considered in establishing eligibility standards will be reconsidered in the identification process.

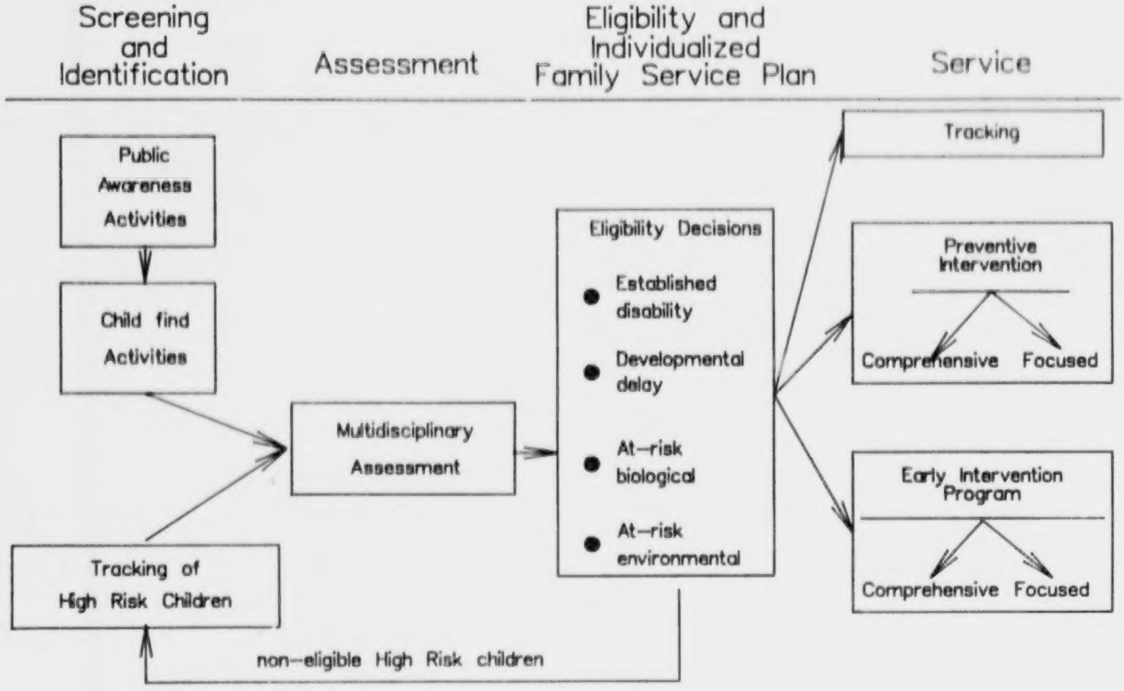
The "System"

Figure 3.1 shows how the public awareness and the identification and screening components feed into the rest of the early intervention service system. The question that must be researched in assessing the proper breadth of the "screening nets" is at least partly related to economics. How many children will be offered the first level of screening? This is a critical question, since the next step, more in-depth multidisciplinary assessment, is a much more expensive one than the screening process. Will states accept a high number of referrals from screening to assessments who do not turn out to be eligible for services?

Public Awareness

The scope and intensity of public awareness activities is an area that must be considered carefully in child find efforts. Serious attention must be given to the action being sought and the individuals who are being asked to carry out the action (Klonglan, 1985). The term public awareness gives the impression that "awareness" of services is the goal. In the case of child find efforts, awareness is not the goal.

Figure 3.1


Screening and Identification
Assessment
Eligibility and Individualized Family Service Plan
Service
Public Awareness Activities
Child find Activities
Tracking of High Risk Children
Multidisciplinary Assessment
Eligibility Decisions
Established disability
Developmental delay
At–risk biological
At–risk environmental
Tracking
Preventive Intervention
Comprehensive
Focused
Early Intervention Program
Comprehensive
Focused
non–eligible High Risk children

The goal is action--the action of parents, professionals, daycare providers and other community members helping to bring children to screenings. Awareness is needed, but there must also be a "sales pitch" that will encourage those with concerns about a child to come to child find activities.

The development of each state's public awareness campaign should be undertaken simultaneously with child find planning to ensure compatibility and continuity. A remark from Washington state's Interim ICC members noted that "Everyone knows to call (911) for emergency services but who in the general public knows what agency, individual or institution to call when they have a concern about a child?" In response to this comment, Washington state is exploring a toll free 800 telephone number to provide information regarding eligibility, child find services, evaluation and parent support. Each state or community should consider providing a 24 hour information line to address the informational needs regarding child health and development.

Special approaches and strategies are needed to reach target populations not well reached through traditional methods such as print media. Each state or trust territory should evaluate the potential population of Part H enrollees in light of the demographic and cultural uniqueness of the population. In some states, public awareness activities will need to be bi- or trilingual, or designed for particular socio-economic, racial, cultural, and ethnic backgrounds.

States and trust territories participating in Part H are required to adhere to nondiscriminatory mandates. At the planning stage of child find activities, every effort should be made to actively involve minority groups in planning and implementation of child find activities. The formation of standing committees to advise the interagency coordinating councils on multicultural, multiethnic issues is a strategy which could provide feedback and dialogue with the minority community.

An example of a program using public awareness effectively is Any Baby Can (ABC) in Austin, Texas. Parents with concerns regarding their child's development can receive initial screening and referral to other services through the ABC program. Key features of the program are the emphasis on its effort to reach *all* families in Austin. The name reflects its non-labeling philosophy. Outreach to families is accomplished via print and television media, as well as advertisements on buses and flyers. Screenings are provided for both English and Spanish speaking families.

Multidisciplinary Screening

P.L. 99-457 offers a radical departure from P.L. 99-142 in the expansion of the role of service providers other than educators. Nine different professionals are specifically mentioned as appropriate providers of service. These professional groups can function as *primary* service providers, rather than adjunct or "support service providers" as their role was defined under P.L. 94-142 (Weiner and Koppelman, 1987).

Under Part H, an infant does not need to qualify for educational services in order to receive support services. The greatly expanded role that these professionals play should be reflected in a multidisciplinary approach to child find. Two strategies can facilitate such child find activities. The first is to make screening activities, clinics, or programs multidisciplinary. The second is to increase awareness, identification and referral of eligible, or potentially eligible infants and toddlers by practitioners not working in the early intervention system per se.

Professionals not working directly in early intervention can assist in the early identification of infants and toddlers for services under Part H. Nutritionists, physical and occupational therapists, and speech/language pathologists may have contact with families and infants who have specific delays or disabilities and may not be known to the educational system. These professionals should be included in the planning of the statewide comprehensive system child find from the initial developmental stages.

At the minimum, state level professional organizations whose members serve infants, toddlers and their families should be included in the initial planning stages of a comprehensive statewide child find system. This can be accomplished through forums, conferences, or meetings which draw together the various professional groups. As an example a recent forum of nutrition professionals serving developmentally disabled clients met at the University of Washington in November, 1987. A product of the meeting was a definition of the role and scope of service to families and clients with developmental disabilities that professionals can provide.

Standing committees representing the variety of service providers involved in the provision of early intervention services may also provide the needed linkage with these professionals. In Washington state professionals, parents, administrators, and others involved in early childhood have formed the Birth to Six Consortium, an outgrowth of the state plan grant. The group provides direct input to the interim interagency coordinating council, as well as receiving information on the council's activities and Part H implementation. The consortium is a strategy for reaching a large and diverse group of professionals who are involved with young infants and toddlers, and their families.

Massachusetts Community Assessment Teams. Massachusetts has a state mandate for early interventions services requiring the department of health to provide, facilitate, and coordinate services to handicapped and at-risk children from birth to three years. Potential recipients of early intervention services in Massachusetts can be identified by a local multidisciplinary team affiliated with the local developmental center. Professionals conduct multidisciplinary assessments and determine eligibility based on assessment data, as well as considerations of established, biologic, and environmental risk conditions. Determination of eligibility is made at the *local level*, rather than by the state legislature, or the coordinator of early childhood services. This approach reinforces the concept of "local norms" in the assessment of developmental disabilities. In addition, the local community assessment team develops the child's individual plan in collaboration with the family. Specific program components are not mandated, but regardless of discipline, services must be family centered, team oriented, and related to developmental outcomes.

Infant Toddler Screening: Tacoma-Pierce County Health Department. The Tacoma-Pierce County Health Department of Tacoma, Washington in collaboration with their local interagency council developed a free developmental screening service available to all children in the county. The emphasis of the screening was to identify infants and toddlers who required further evaluation or follow up. Infant-toddler screening is a "first look" at children who may not be developing to their greatest potential.

A screening protocol was developed with input from professionals representing physical and occupational therapy, nursing, developmental pediatrics, nutrition, early childhood education, social work, psychology, audiology, and speech/language pathology. The protocols were developed to be low cost, fun for the infants, toddlers, and parents, and quick in terms of professional time. The screening protocol takes between thirty and forty-five minutes to complete.

The success of the program can be partially attributed to the fact that screenings were conducted in locations where infants and toddlers are most likely to be found---shopping malls, grocery stores, and child care centers. Reaching parents not likely to discover screening services on their own was a major objective of the Infant Toddler Screening Program.

Connecticut Infant-Toddler Developmental Assessment Program (IDA). The Connecticut Infant-Toddler Developmental Assessment program (IDA) based at the Yale University Child Study Center (Provence, et al., 1987) was designed to meet the increasing need for multidisciplinary assessments of young children.

Program developers have attempted to bridge the gap between screenings and complex multidisciplinary evaluations. The IDA program is comprised of two parts 1) the first part is a broad-based integrative process approach to developmental assessment targeted to at-risk and disabled children who are in need of early intervention services or monitoring. The second is a continuing education program which trains professionals to conduct the IDA assessments.

The IDA assessment strategy utilizes professionals based in community agencies such as well child clinics, early intervention programs, or hospital follow-up clinics who may already be providing developmental assessments. Working in an interdisciplinary team of two, functioning as developmental generalists, the integrated assessment process targets health, family-social and developmental dimensions. Emotional domains are covered in the developmental portion of the assessment.

The IDA assessment provides an integrated summary of health, family, and developmental findings. A plan for the child and family is then developed in concert with the family.

The approach has been demonstrated to be a cost-effective, reliable approach to address the need for early multidisciplinary assessment of young children. The IDA Program provides a systematic approach to identification and assessment along multiple lines of development. Further, using the services of professionals within the community in a collaborative assessment promotes local ownership of the program and interagency communication and collaboration. Further information on the IDA Program can be obtained through Joanna Erickson, MPH, at the Yale University Child Study Center, P.O. Box 333, New Haven, Connecticut, (203) 785-2513.

Tracking Systems

Due to rapid changes in development during the first three years of life, a need for services might be identified at a few weeks of age or not for months. Annual or even semi-annual child find activities that are currently conducted for preschool children are clearly not appropriate for infants and toddlers. The screenings done in conjunction with Public Law 94-142 will not meet the needs of this population. A "rolling" or ongoing system of child find is needed which permits the identification of infants and toddlers at the earliest possible time for referral to further screening or assessment. This approach is geared toward the identification of potential recipients of early intervention, as well as identification of infants who are in immediate need of service. The identification of potential recipients is accomplished through the use of tracking or monitoring programs. Infants and toddlers in immediate need of services are identified primarily by screening activities which occur at multiple timepoints and locations and can be carried out by a wide variety of agencies and professionals.

Warning Signals (Blackman 1986) outlines the objectives and benefits of a tracking system. A tracking system manages data collected:

From
- hospitals
- private physicians or other health care professionals
- educational programs
- therapists
- social service agencies
- vital records and other registries

Regarding
- children who have discernable disabilities or chronic illness
- children who are believed to be "at-risk" for later developing or who manifest a disabling condition or chronic illness

Through
- screening projects
- health service delivery
- social care, including day care

For The Purpose Of

- ensuring the children with disabilities and chronic illness and identified as early as possible
- referral to an appropriate service agency or treatment facility
- ensuring that individual children are not "lost" to the service system
- determining future personnel needs
- understanding developmental outcomes of children who risk factors
- understanding developmental outcomes of children who were differently managed in different care systems
- identifying personnel training needs

A number of states currently have tracking or monitoring programs which promote the concept of surveillance for potential disabilities during the first three years and beyond.

Iowa. Iowa's High Risk Infant Follow-up Program has successfully tracked infants since the late 70's. Infants are identified in the neonatal intensive care nursery (NICU) and followed by regional clinics until age 8. Developmental assessment occurs at ongoing intervals throughout early childhood at 4, 9, 18 and 30 months of age, kindergarten entry and eight years. Infants requiring further evaluation are referred to state educational services, which are responsible for mandated 0-3 early intervention services. It should be noted that the eligibility criteria for the Iowa program do not include environmental, social or parenting risk factors, unless the infant is returning to an environment of extreme psychosocial concern, and includes only infants identified from neonatal intensive care units.

Oregon. The Oregon Developmental Monitoring Program (ODMP) draws upon the expertise and observational abilities of parents through the use of developmental questionnaires. Infants eligible for the ODMP are infants determined to be "at risk" due to biological or environmental concerns. Most enrollees have spent some time in a neonatal intensive care unit. After enrollment, parents are mailed a series of questionnaires when their children reaches 4, 8, 12, 16, 20, 24, 30, or 36 months of age.

Each of the eight questionnaires is identical in format and covers five assessment areas: communication, gross motor, fine motor, adaptive, and personal-social. In addition, general questions regarding feeding, sleeping, and parental concerns are included. Parents who require additional assistance in completing or returning the form are contacted by telephone, and provided the option of completing the questionnaire via telephone.

Completed, returned forms are then scored to determine the infant's or toddler's developmental status. Questionnaires are scored to yield one of two ratings, normal or abnormal. The families of infants who receive normal ratings are notified by mail. Infants who are categorized as abnormal are offered additional follow-up. Parents are contacted and invited to return to the developmental center for further assessment.

The Oregon Developmental Monitoring program has been shown to be a reliable, valid, and cost effective method for accessing parental information and expertise for early identification of children in need of additional evaluation or services (Bricker, 1987).

Utah. Utah has developed a computer assisted information system as part of the Utah Registry for Handicapped Persons of the Interagency Management System for the Handicapped (IMISH). Implementation of the system will coordinate information regarding individuals with disabilities from birth through death who require services from health, education, and social services departments. A common central registry form and information exchange between participating agencies is used. The Utah registry is not a tracking system per se, but could be a component of such a system. A great deal of confusion exists regarding operational definition of the terms "tracking" and "central registry." Adding to the confusion is the often interchangeable use of both terms in the literature. The use of the term "tracking, or tracking system" in this document refers to a process of monitoring infants and toddlers. A registry, or central registry, is a data base regarding individuals whom are disabled, or are at risk of developmental disability. A registry might be viewed as a centralized clearinghouse for persons requiring services.

Washington. In Washington state, infants who present one or more established, biological, or environmental risk conditions with the first 30 days of life are eligible for the High Priority Infant Tracking Program (HPIT). Monitoring of both health and developmental progress is coordinated through local primary care providers at 6, 12, 18, 24, and 36 months. Infants born in local community hospitals as well as intensive care nurseries are included in the Washington State Program. Follow-up is focused on maintaining the "at-risk" infant in ongoing well child care for health maintenance and developmental monitoring. Medical care providers have the opportunity to develop long term, enduring relationships with families and young children. The Washington State High Priority Infant Tracking Program seeks to complement this relationship by ensuring that infants at risk remain in well child care, and receive additional follow-up or services as necessary.

Additional information on Iowa, Washington, and Utah programs can be found in **Keeping Track: Tracking Systems for High Risk Infants and Children** (NCCIP, 1985). Other states provide limited monitoring programs for specific groups of infants, such as graduates from neonatal intensive care units (NICU), infants who have diagnosed conditions such as PKU, or premature infants.

A tracking or monitoring system is a critical component in the development of a truly comprehensive child find system. While it is fully recognized that any system which identifies infants using perinatal factors such as prematurity or low birth weight will identify only a small minority of the infants and toddlers who require early intervention, the benefits of identification and monitoring help to assure the timely recognition of those that do need services. The information gained from tracking prospective users of early intervention services will be useful in the design and development of programs to identify which children need early services, and projecting the numbers of children needing services.

Shared Responsibility for Child find

Child find activities to reach young children eligible for services under Part H should be a responsibility of all state and community agencies serving this population. The responsibilities and expectations of each agency at the state and local community level should be clearly delineated. Clear expectations, and a vision for what the final outcome of child find is should be built into the child find program strategy. A process for ongoing review, revision and evaluation of collaborative child find activities should be considered early in the planning process, and the evaluation component should be shared with all participating agencies for review and comment.

Planning must include a thorough cataloging of child find activities already going on in states and local communities. Most states will have some elements that need to be coordinated and tied in with new efforts. A thorough "cataloging" of such activities within the states should be part of planning the child find component of the new system. Duplication of efforts in not only wasteful to the system, but confusing and discouraging to parents.

Some of the child find resources that need to be included are parents, hospitals, childcare settings, EPSDT, Pediatricians, family physicians and other medical specialists, birth registries, WIC, and MCH programs and tertiary clinics.

Parents. Parents are critical participants in child find activities. Efforts and strategies to include parents in the identification, screening, and assessment of infants and toddlers should be included at every level of planning and development. Parents have the unique opportunity to observe their children over time and in a variety of environments and situations. Their knowledge of their child's skills, abilities, strengths, areas of need should be included in any child find protocol.

An analysis of local norms is very important in assessing how to encourage parents who suspect their child may have problems. Are there language and cultural differences that have to be understood to plan public awareness efforts? How is it possible to diminish the stigma of disability, to see the child find process as more routine? Are there problems with the reputation of particular agencies or services in the community that must be changed to accomplish quality child find activities? Representatives of the range of parents who need to be reached should be involved in child find planning efforts.

Hospitals. Over 96% of children in the United States are now born in hospitals. The relationship between child find activities and hospitals needs to be a strong one if children born with either disabilities or risk factors are to come in contact with the early intervention service system. This includes children served in NICU, PICU and other specialized care units. However, it is important to remember that only a small percent, perhaps 20%, of children served under P.L. 99-457 will be identified as needing services at birth. Without out-of-hospital child find activities most children in need would not come to the attention of services until screenings associated with school entry.

Child Care Settings. Linkages between child care, nursery schools and private child care settings for the growing number of young children who spend time in out-of-home care is another essential target for child find activities. Local and state child care associations should have representatives in child find planning efforts. Efforts to reach all child care providers should be part of public awareness activities.

EPSDT. The Early, Periodic Screening, Diagnosis and Treatment program was initiated in 1967 to provide Medicaid eligible children from birth to 21 with ongoing health and developmental monitoring and treatment. The 20 year history of the EPSDT program is fraught with administrative, financial, and technical problems which have been comprehensively chronicled by Meisels (1984). However, rather than discarding the system altogether, he feels we should mobilize to reorganize and redefine the EPSDT program to better meet the needs of infants and toddlers. Believing that "...EPSDT represents the only federal legislation mandating developmental screening for the purpose of prevention...even with all it's technical problems, developmental screening in EPSDT is justified by the cost-benefit logic of prevention."

Each Interagency Coordinating Council (ICC) should carefully evaluate the effectiveness of EPSDT at the state level and attempt to integrate the system into a component of a comprehensive child find system. This task will not be without challenges as EPSDT is a federal program which is administrated by the states. States are viewed as the "senior partner" and are permitted to assign administrative responsibility to a specific state agency. Across the country EPSDT might be administered by as many as 20 different agencies. While fragmentation of services across the country is a result of this policy, this may permit the ICCs to provide leadership for the restructuring of their individual states EPSDT programs to increase the visibility and applicability of the program to identify young infants and toddlers with disabilities.

Pediatricians and Other Physicians. Another obvious source of identification of children with special developmental needs would be through the health care system. Most children have regular contact with a pediatrician or other health provider through 18 months of age, essentially the time period of immunization programs (Knutsen et al., 1987). After that, studies have shown that only 50% of this nation's two-year-olds have a regular health care source (Blackman, 1986). Pediatricians should be seen as a critical source of identification of children during these early years, and awareness and education should be directed specifically to them.

Efforts to reach children and families with infants and toddlers should be targeted toward the first two years of life. Outreach activities to community physicians, community healthcare clinics, and local health departments' well child clinics can help to provide timely identification of infants who are eligible for service. Health care professionals are often the first professionals to learn of concerns regarding a child's developmental status, as many parents first approach a health care provider with questions about their child's development. Collaborative efforts to enhance the early identification and referral of infants and toddlers for services are required.

The New Jersey University Affiliated Program based at Rutgers University under the direction of Dr. Deborah Spitalnick developed a model system of outreach to community physicians to increase awareness of early intervention services, and increase the number of referrals to programs. The model program was comprised of three parts.

1. **Lecture Series**
   A prepared slide/text lecture series on the subject of early intervention was presented by members of the medical community who had demonstrated interest and leadership in the area of early identification, assessment, and intervention of young children. The content of the lectures was controlled for consistency. The guest lecturers presented the information at grand rounds, medical meetings, conferences, or courses where continuing medical

education (CME) credits were offered. The lecture series attempted to reach physicians at meetings were likely to attend, rather than holding a special meeting, and used peer experts to deliver the information.

2. **Written Materials**
   Outreach Project Staff prepared a journal article regarding early intervention in New Jersey. This article was inserted into the major state medical journals.

3. **Developmental Assessment Kit**
   Imitating the techniques of pharmaceutical companies, outreach project staff made individual appointments with physicians to deliver and explain the use of the developmental assessment kit. The kit contained parent information in English and Spanish regarding development, the Denver Developmental Screening Test, and uniform referral forms for early intervention services.

Spitalnick reported that the program was successful because it created a forum for physicians and parents to discuss a child's development. Because the kits do not require the physician to make a diagnosis, but rather screen children for further evaluation, the process is seen as less intrusive, and more acceptable to the medical community.

The success of the program has been demonstrated by an increased number of physician referrals to New Jersey's EI programs and multiple requests for replacement pieces for the screening kits. The model developed by UAP-Rutgers has excellent potential for replication in other states and trust territories.

Birth Certificates. Birth certificate data has traditionally been a less than optimal strategy for identification of infants with existing or potential disabilities. Numerous problems with the accuracy of birth certificate data were reported by Frost, et al. (1984). Conditions such as cleft lip and palate or spina bifida, although easily diagnosed at birth, are often omitted from the birth certificate. The problems reported by Frost are further complicated by the fact that the responsibility for completing the birth certificate may vary from county to county, hospital to hospital. In some location the attending physician may complete the certificate, but a ward clerk, nurse aide, or staff nurse might also be responsible, contributing to uneven reporting. These problems are further compounded by the long delays in processing and recording birth certificates.

Despite the problems noted above, all states require the reporting of live births. The potential utility of this information in a comprehensive child find system is significant. Several states have developed effective systems for improving the accuracy and utility of birth certificate information. In Utah, under the SKI-HI Program, birth certificate information is routinely reviewed for potential indicators of hearing impairment. If a child is found to be at risk for hearing impairment based on a set of criteria found on the birth certificate, follow up activities in the form of parent questionnaires are initiated to monitor the child. In Washington state, birth certificate data is crossed matched with entries to the Birth Defects Monitoring Program to ensure all newborns are accurately identified. This program was further enhanced by the establishment in 1987 of an automated Vital Statistics Birth Certificate System which reduced turn around time to clients from six weeks to two days.

WIC and other nutritional support programs. The Special Supplemental Food Program for Women, Infants and Children (WIC) remains an underutilized and potentially significant resource for child find. WIC was initiated in the early 1970's by the Department of Agriculture to fund agencies to distribute either coupons, which can be redeemed for specific foods, or the specific foods themselves. Nutritional screening, counseling, and food supplements are provided to income-eligible pregnant and lactating women, and children to age five. The actual age limit for children however can vary greatly from state to state, and even within a state children in different counties may receive unequal amounts of service. The lack of parity is due to financial constraints in some communities. The WIC program requires a state match of funds in addition to the federal dollars.

Because the target population of the WIC program is mothers and children who are at increased nutritional risk and meet income eligibility requirements, the WIC program represents a primary prevention strategy to improve the outcome of infants. WIC can be an important link in a comprehensive child find system by providing not only primary prevention, but also be providing secondary prevention activities through ongoing screening, counseling, and follow-up of mothers with young infants.

The potential for utilizing nutritional professionals in child find activities was a continuing theme in the community nutrition forum at the University of Washington in November 1987. Feeding, weight gain, or growth problems may be the earliest indicators of potential disability in a young child. These types of concerns are primarily referred to nutrition professionals. The consortium of professionals reiterated that they can identify children at nutritional risk who without appropriate intervention may go on to develop developmental concerns due to inadequate nutrition. This is of particular concern in addressing the growing numbers of infants identified as failure to thrive. The link between adequate nutrition as a necessary prerequisite for normal growth and development has been well documented. Peggy Pipes, Chief of Nutrition at the Child Development and Mental Retardation Center at the University of Washington commented, "We should be able to identify those children who are at risk for nutritional concerns by six months--if they are at risk nutritionally, they are at risk developmentally." The WIC program service population by virtue of the income eligibility requirement may be thought of as potentially at increased environmental risk due to limited financial resources. The Washington State High Priority Infant Tracking Program has documented the WIC Nutritional Support Program as one of the three most commonly used services by families of high-risk infants.

Collaboration with nutritional screening and support programs such as the WIC program is strongly recommended as part of the ICCs total state strategy. In addition, Nutritional professionals with training and expertise in serving clients with developmental disabilities should be involved in compressive planning of statewide Child find.

Bureau of Maternal and Child Health. The Bureau of Maternal and Child Health's state Title V crippled children's services, now known as programs for children with special health care needs, have a long history of involvement with child find activities. The Bureau is encouraging all its programs to become active participants in the P.L. 99-457 implementation process and many are prime players in state lead agency's. A number of states already have identification efforts run through MCH programs, such as metabolic screenings and screenings for hearing impairments, and will be important resources in expanding identification activities.

UAP Follow-up and Assessment Clinic. American Association of University Affiliated Programs (AAUAP) provides screening, follow-up and assessment clinics for developmentally disabled or at-risk children as part of their activities. Programs such as the Intensive Newborn Care Program at the Mailman Center at the University of Miami School of Medicine, the Neonatal Intensive Care Unit Follow-up Clinic at Eastern Maine Medical Center in Bangor and the University of Washington High Risk Infant Follow-up Clinic in Seattle provide ongoing monitoring of potentially eligible infants. The UAP programs can be an important resource to the states in planning the child find component of the Part H system.

SUMMARY

Realistically, child find efforts can be structured to limit the number of children who will be in need of services. With the estimates of potentially eligible children on one hand and the estimates of service resources on the other, it may be tempting to take this approach. But child find activities with a strong public awareness component, ongoing screening resources and links with a wide variety of community child care components can, in addition to their identification role, serve as a prevention service, as support for concerned parents and as a way to broaden public support for early intervention services.

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CHAPTER 4

What strengths and needs do these children and families have?

Evaluation

How do we know what services or resources would benefit a child with special needs and his or her family? The traditional first step has been an "evaluation." Our sense of what evaluation means for children is growing in important ways. We are not as rigid. We are learning to look at evaluation techniques that will be useful in planning ways to improve levels of functioning, social skills, and adaptive skills, rather than making the child a dot on a scale. Parents, whether their children have disabilities or not, now expect evaluations of their children at some point. It has become routine, despite its meaning of "placing a value on something."

But with the Individualized Family Service Plan (IFSP) in Public Law 99-457 we are entering a new application of the term "evaluations." We are not just talking about assessing the strengths and needs of children but about assessing the family's strengths and needs as well. This is a change of great significance. On the one hand, it is a dramatic and long sought public acknowledgement that the family is the most important resource for encouraging a child's potential, and families should have the resources needed to do that. The premise behind this approach is that with the right kind of resources, **every** family can support the development of a special needs child; the service system is to support, not supplant, the family. On the other hand, while parents may not relish the evaluations of their children, they are apt to be considerably more sensitive about having themselves and their parenting skills evaluated.

"I would find a family-focused form offensive if it were going to be collected with data and you get a score at the end," says one mother. "I think we are already doing family evaluations in a really informal way. When you have a home intervention teacher walk into your house she has already made a judgment by the time she gets through your living room and that's exactly what she does and that's why my cleaning day is right before the day she comes, and that's the truth. She's already making a judgment. I think home intervention teachers are probably the most skilled people at looking for the strengths and weaknesses of a family so that they can, if they are skilled, utilize what they are seeing. What we're saying now is that we have to take that information and put it down on a piece of paper so that other people who are trying to provide services can see what they see. That's why many of us treasure our home intervention teacher at our staffing as the one person who really knows us." But other parents may be less enthusiastic. Another parent reacts, "Do I need counseling? Well, am I being counseled for my marriage or my child, for my finances, for my psyche, my hygiene? This is a deficit model, you know. The stereotype is that evaluations are for poor confused people."

Perhaps more than any other aspect of this legislation, it will take wisdom to navigate between the good of having families be part of the evaluation component, and the dangers of inappropriate intrusion. It will also be a delicate feat to carry out family needs assessments without further contributing to the sense that some parents of children with disabilities already have that they, too, have something wrong with them. The key will certainly be in the degree to which parents sense the equal partnership and collaboration with professionals for the child's benefit that the law intends. Two of the fourteen minimum requirements for the law relate to evaluations of children and families. Section 676(b)3 calls for:

> A timely comprehensive multidisciplinary evaluation of the functioning of each handicapped infant and toddler in the state and the needs of the families to appropriately assist in the development of the handicapped infant and toddler.

Section 676(a)(4) states that each handicapped infant and toddler in the state will have an Individualized Family Service Plan. Section 677(a)(1), which describes in detail the content of the plan, calls for each handicapped infant or toddler and the infant or toddler's family to receive -- "...A multidisciplinary assessment of unique needs and strengths and the identification of services appropriate to meet such needs."

In this chapter we will look at some of the issues inherent in evaluation questions.

Desribing The Focus of Evaluation

Who are we focusing on, the child or the family? While the mandate of the law clearly says "family," along with the child, this will represent a significant departure for most states in how they look at what is known as early intervention. One of the characteristics of an individual state's implementation of the law will be the degree to which the focus is shifted from the child only, to the child and family unit.

Recent research has emphasized the need for a family focus in early intervention efforts, in order to facilitate child change (Dunst, 1986; Foster, Berger, and McLean, 1981). The importance of the home environment, the social supports available to the family, and family characteristics and demographics are especially important factors in effective intervention with infants and toddlers who have severe or multiple disabilities (Dunst, 1986). Recognizing that the family is the primary environment for the child, the Division of Early Childhood of the Council for Exceptional Children (DEC) stated that services must support rather than supplant the family role. Therefore, the DEC recommends that family focused services should be directed to the needs of the family, as well as the child (DEC Position Statements, 1987).

How can we describe family needs? Areas that might need to be considered have been outlined by Trivette et al. (1986) in Table 4.1. But families with a child who is at risk for or has a disability may have special variations on the needs of families in general. For example, a child with physical impairments may require specially designed equipment or adaptive devices which the family lacks the financial resources to provide. Children with severe disabilities may require highly specialized care (such as trachesostomy suction, gastrostomy tube feeding, urninary bladder catherization) which makes child care more difficult to secure. In order to facilitate their adjustment to having a child with a disability, the family may need access to counseling or parent support groups to help them cope with added levels of stress.

Other potential needs of families may be related to individual family demographics. Unemployment, poverty, substance abuse, teen or single parenthood can impact significantly on family stress levels and the ability to access or benefit from early intervention services designed to facilitate **child** change.

Describing The Family

States will have to decide how they will define family, who it is that needs to be assessed for strengths and needs along with the child.

In the last two decades, the composition of the American family has changed significantly. The increase in teenage and single parent families, in addition to step families and dual career families, has greatly increased the variability of family units. Because of these trends, many children are spending significant portions of time with a range of people who are not immediate family members (child care providers, grandparents, unrelated significant others). Given the potential impact of these people on a child's daily life, their participation in the development of the IFSP should be carefully considered.

Figure 4.1

Framework for Assessing Family Needs

Family Functions	Needs
Economic	Adequate amounts of money Ability to budget money wisely Funds to purchase necessities
Physical	Adequate nutrition, clean air, and water Adequate housing (space, safety, warmth, furnishings, etc.) Safe neighborhood, police and fire protection Access to preventive and therapeutic medical and dental care Access to telephone; public or private transportation
Vocational	Gratifying work (employment) in and out of the home Opportunities for learning new skills and for personal achievement
Recreational	Time for daily rest and opportunities for activities other than work and home responsibilities
Educational	Time and adequate materials for developing the child(ren's) knowledge, abilities, and skills Opportunities for adult education
Emotional	Positive relationships among family members and with others outside the family that offer expression of affection, respect, and support
Cultural/Social	Meaningful communications and interactions with extended family, neighbors, friends, and community Opportunities to share ethnic or value-related experiences with others

Trivette et al., 1986.

Questions arising from a less restrictive definition of a child's family include: Who should be included in services provided to a family member? What are the limitations on family needs assessments? Should the definitions of "family" be determined on an individual basis or should a standard definition be applied? How should individual family values be reflected in the IFSP? One family consists of the mother, her two children, one with a disability, and her live-in boyfriend. Both children view the boyfriend as a father figure and he demonstrates regular interest and concern about the intervention program for the child with a disability. He is unemployed and the mother is employed full-time. He frequently attends team meetings, visits the early intervention program and energetically urges that additional services be provided for the child. Should he be considered a participating member of the IFSP team? Should **his** needs and strengths be assessed and included on the IFSP? What happens if his relationship with the child's mother ends?

Another family consists of two parents, both of whom work outside the home, and one young child with a disability. The child spends approximately 12 hours per day in a family child care setting outside of his own home. Should the care provider's home be considered the child's primary environment? Should the caregiver's strengths and needs be evaluated and included as part of the IFSP?

Ethnic and cultural circumstances should play a strong role in determining who is in a position to influence the child's development. For example, O'Connell (1985) emphasizes the importance of considering the strong role of the maternal grandmother in child rearing in the White Mountain Apache community in Arizona. Young mothers use their own mothers as primary sources of advice and this advice may conflict with what is learned from early intervention professionals. Such a strong figure, then, would need to be considered in the IFSP process.

These issues of family definition should be resolved within the context of the law's purpose in using a family-centered mode: Developing the best scenario for positively influencing the child's development.

Defining Multidisciplinary Evaluation

Clearly, the professionals who participate in family-based multidisciplinary assessments should have demonstrated competencies in working with parents and families. How many disciplines should be represented is a question to be decided by each state. More can mean more expertise and experience with a range of families. Potential disadvantages would be in increasing the number of different professionals with whom the family must interact and further increasing the need for communication between professionals. Parents of young children with disabilities often report that they feel a special closeness or rapport with a particular early intervention professional. They tend to view this person as a source of information, advice and support when dealing with other professionals.

Conflict of interest issues are important in the choice of evaluation staff. Is the evaluating person the same person who will deliver services? If this person knows there are no occupational therapy services available, how will the integrity of the evaluation be protected?

"You have limited options for getting the kind of evaluation that's relevant to the family, not relevant to the professionals," says one parent "They're fitting the needs to their program. We have to conform our needs or disability into these groups where it should be the other way around. Things should fit us, not them." Creating early services that respond to the individualized needs of families, rather than fitting into existing service structure, will involve ongoing vigilance. The differences are not always easy for professionals to see or, once seen, to carry out.

Regardless of which specific professionals carry out the family based assessment, parents and other involved family members must be part of the process. The family's evaluation of its own needs should be a major emphasis.

The law is less specific about the areas that should be covered in the family part of the IFSP evaluations. An area of great debate has been the relationship between a need identified on the IFSP and a requirement that resources be provided to meet that need. The spectra of early intervention professionals having to find jobs, housing, alcohol treatment and marriage counseling for the families of eligible children has caused a great deal of uneasiness. There is basic support now for the idea that anything the family feels is a need should be included in that portion of the IFSP. The family is rightly placed then as the best evaluator of their own needs. It would then be up to the case manager to communicate with agencies that provide those services.

One parent says, "Maybe the first thing is to define who needs the most help. Is it the parent or the child? Because if you have an aggressive parent that is going to go to the library and read all the books and stuff like that, and has a good attitude or whatever, then maybe your concentration would be different than if you had a parent who was denying the disability or that type of thing. So maybe define who needs what."

"I like the idea of me or my family being allowed to determine what our needs are," says another parent. "Who is more in need of support right now? Is it my son or is it me? Is it the rest of us? I don't want a professional telling me I've got it all together, that I don't need any kind of help, that we're cool, because maybe we're not. They don't know what it's like in my family once I leave their office and they don't know what my coping skills are or my lack of them right now. You see I can smile, but you don't know what's going on inside of me right now. Can I make that choice about whether I need some kind of additional support?"

Many parents talk about the need for professionals to understand in concrete terms the effect of a special needs child on everyday functioning. "There are so many roles to learn for a parent of a special needs child. There is case manager, advocate, there's teacher, there's emotional nurturing. But, I think if I were to sit down and write down all the different things I do for my disabled child, that I do for myself, that I do for my spouse and my other children, that, if everyone did that, and we sort of put it down and you could see how many different things I do, you could be amazed. We're now working on this special diet, and we're working on these functional skills at home and we're working on a couple of conceptual things like a calendar of daily activities and are acquiring personal self-help skills and hygiene skills that might not be typical for other children. The evaluation has to make room for these things about family life."

"You have to, in the evaluation, talk not just about whether you can get a babysitter, but if you do, how **hard** it is," reports a father. "As soon as I told a babysitter anything about Katie having cerebral palsy they would say, 'Gee, I don't know about that.' I say 'You just handle her really normal, if she falls on the floor she just falls on the floor, no big deal.' But it would really turn them off. I think parents really need just some place to go at least once a month that's not a big deal to arrange."

Isolation is often a factor in family life with a special needs child. "Aloneness is a common result and parent support is seen as one important way through it. I think every parent probably needs to be in touch with other parents in the same situations. I think that you just feel so alone because nothing like this had ever happened to any friends or family and we just felt like we were in this tremendous void until we were able to meet other families. And we did get a lot of other information from those families, but the most important thing was just being put in touch with them."

"I ache for the people who aren't meeting the right people, who are feeling lost," reports another parent. "I wasn't one of them because pretty quick I started making phone calls, and saying, 'Hi, I've got a developmentally disabled child. Can I come play?' I just started reaching out. But for everyone of us loudmouths there are probably dozens of people who are just not knowing what, when, who or how to ask. You don't know what you don't know."

Evaluating Strengths

The language in the law that calls for strengths as well as needs to be included in the evaluation is an important step in balancing the "deficit" model. It presents, however, some interesting new challenges. It will naturally be a shift to seek out strengths when professionals are keyed to looking at problems, deficits to be filled by services. It is critical that families and children not be seen as accumulations of problems. But of equal importance to the family is the question of how those strengths will be used and interpreted in the service plan.

"I see strengths in a different way," reports one mother. "One of the things that irks me is that I have a non-disabled child who is five and starting kindergarten and then I have a child who will be three who is disabled. I see the five-year-old's program being designed around her strengths. She is talented and gifted, and the things that make her feel best, they work on. With my child who is receiving special services they look at the weaknesses and work on those whether there are strong areas there or not. The strengths are not being utilized. So for me, when he was one and not walking I wanted to know why he was not walking. Now that he's three and not walking, it's secondary to me, but his social skills are so good and his communication is so good that I'd like to work on that and for my family that's a strength, but don't **ignore** it. Tell me, as we identify these strengths, what we are going to do with them. Talents need promotion or they die."

Some parents have concerns for how their family strengths will be viewed as well. "Why are we looking at the strengths? For what purpose? To eliminate those needs for services? If I put down on a questionnaire that I have a very strong self-esteem and somebody looks at that and says, 'All right, she doesn't need counseling.' Or if I write down that we have an excellent way of handling meals at our house so we really don't need occupational therapy because we are disciplined about the way we approach our meal time, even though my son is eligible for those services, you can eliminate occupational therapy services. That's one more thing we don't give this family. That's the danger I see with listing strengths."

A third concern is the elusive and delicate nature, the sometimes spiritual quality, that make up family strengths. There is a danger of trivializing those qualities in reports and evaluations.

"When I think of strengths in our family, the first things that comes to my mind are resilience and tolerance, but how can you quantify those? Shall we work on resilience for the next six months? I understand the point here. It is bad for families to be seen as bags of problems. It is bad for the kids. But lets not take away the magic."

Evaluation Of Finances

Finances need to be carefully explored, for even in families relatively well covered by insurance and public program, the child with special needs can be a serious drain on financial resources. Along with grief and social isolation, finances can add to the stress that makes such families especially vulnerable. Some of these out of pocket expenses can include: transportation, parking, housing, meals, for out of town hospital stays, drugs, lost wages due to illness, loss of second income because of care demand, equipment, diapers, home adjustments, special diets. Part of the services for families might include exploring both public and private options for some of these special needs.

Carrying Out The Evaluations

The individual family service plan, the IFSP, is seen by many to be the driving force behind the law. The evaluation component of the plan, identifying the strengths and needs in both the child and family, and the language used to articulate those needs and strengths will be used to determine what resources or services are needed to help further the goal of maximizing the child's development.

As of now, we do not have examples of the IFSP, because it was created in this law. Many people are at work to help states determine what will go into their IFSP and we do not want to suggest at this early stage that we have examples of the IFSP per se. It is clear that an appropriate balance must be developed between formal processes of evaluation--which contribute to administrative efficiency, consistency and planning--and informal evaluations which come from observant and articulate parents and professionals and are often the key to truly individualized services. As one social worker warns, "First do no harm! Don't just go to a family with checklists. Don't count toys." A very practical element in carrying out family-centered evaluations may be the scheduling of them. Will they have to fit in to the professionals normal nine to five work day? Will evening or weekend times be made available? These decisions can set the tone for how meaningfully the response to family needs will be.

Child evaluations. The law calls for evaluations of the infant's or toddler's present level of physical development, cognitive development, language and speech development, psychosocial development, and self-help skills, based on acceptable objective criteria. Some groups would like to see health assessments included as well. Among the instruments that might be used include:

Assessment in Infancy: Ordinal Scale of Psychological Development (Uzgiriz & Hunt)

Bayley Scales of Infant Development (Bayley, 1969)

Carolina Development Profile (Lillie and Harbin, 1975)

Denver Development Screening Test (Frankenburg et al., 1973)

Diagnostic Inventory of Early Development (Brigance, 1978)

Hawaii Early Learning Profile (Enrichment Project for Handicapped Infants, 1979)

Learning Accomplishment Profile: Diagnostic Edition (LeMay et al., 1975)

McCarthy Scales of Children's Abilities (McCarthy, 1972)

Parent Inventory of Child Development in Non-school Environments (Vincent et al., 1983)

Preschool Attainment Record (Dall, 1966).

Portage Guide to Early Education (Bluma et al., 1976)

Stanford Binet Intelligence Scale (Terman and Merrill, 1973)

Uniform Performance Assessment System (Haring et al., 1981)

Observation opportunities which involve the parents and professionals in interdisciplinary discussion of what is being observed are an important part of child evaluations. In addition, where possible, opportunities to observe the child in "natural" settings such as home or preschool, would be desirable.

Family evaluations. For evaluating family strengths and needs, below is a sampling of instruments that might be used in whole or in part. It is the hope among many parents and practitioners that the regulations affecting P.L. 99-457 will not **require** the IFSP to be in a written form. While in many cases, a written record will be useful and appropriate, the decision about the form of the IFSP should be what the family feels most comfortable contributing to, and that each case will be highly individual. The IFSP should reflect the relationship between the family and responsive professionals and change flexibly as the families needs change.

Daily Routine Recording Procedures (Vincent et al., 1983)

Home Observation and Measurement of the Environment Scale (Bradley and Caldwell, 1979)

Model Family Needs Assessment Process, Administration for Children, Youth and Families, (Head Start Bureau)

Support Functions Scale (Trivette and Dunst, 1985)

Survey of Family Needs (Bailey, et al., 1986)

SUMMARY

It is through the informal processes--the setting, the relationship between the family and whatever professionals are involved--that the worth of the family evaluation component will rest. The intent of the bill is to promote a collaborative effort, a combination of resources, between the family and the service community to promote the welfare of the child. Professionals and parents will enter this new territory with trepidation, and with good reason. The test will be whether families going through the IFSP process do in fact feel "evaluated" or supported.

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CHAPTER 5

How will the needs of children and families be met?

Establishing goals, identifying a case manager

In the last section, issues related to evaluating the needs and strengths of children and family were discussed. If the identification of child and family needs and strengths has been a genuinely individualized one, services and resources must then be identified that can respond to those needs. In this section we will be looking at elements of the Individualized Family Service Plan (IFSP) that deal with determining what child and family outcomes are to be, and with the role of the case manager identified during the IFSP process.

After the evaluation, the IFSP calls for a statement of the following:

- Major outcomes expected to be achieved for the child and family.
- The criteria, procedures and time-lines used to determine progress.
- A statement of the specific services required to meet the unique needs of the child and family, including the method, frequency and intensity of delivering services.
- The projected dates for the initiation of services and the anticipated duration of services.
- The name of the case manager who will be responsible for implementing the plan and a plan for transition from Part H programs to preschool programs.

Outcomes

Planners must be cautious in projecting the outcome of early intervention services. Pat Welge, Coordinator of Infant Services at the Louisiana State University-UAP commented that "we sold ourselves short, we said we could change IQ scores through early intervention. We should have said we can help children become more functional, independent, and offer family support--that's what early intervention can provide."

The way that family and child goals are expressed can range from the expansive to the very specific style characteristic of the IEP. In addition decisions will have to be made about whether family goals will be a separate entity, or whether child and family goals will be integrated.

The legislation states that criteria, procedures and time-lines for determining progress must be included in the IFSP, and that the plan should be reviewed at least every six months. Additional requirements regarding the goals and objectives need to be determined. Should achievement goals, or developmental goals, be established for one year or some other time period? Will exact procedures (teaching strategies, counseling techniques) be specified? Will the goals and objectives be written to accommodate potential changes in service providers without requiring the development of a new IFSP?

An example of an outcome of family-based services might be to keep a child with severe disabilities at home rather than in an institution. Services such as respite care, counseling and parent training have been effective in helping families maintain children with disabilities in their family homes. An illustration of an outcome resulting in child change is provided by the case of a parent who received regular respite care for her child. The relief from care allowed the mother to feel more in control, more calm and she began to implement recommended programs in the areas of physical mobility and communication. The child's rate of progress in these areas increased correspondingly.

While for professionals the distinction between family goals and child goals may be real, parents tend to blend the two. Parents often see professionals as helping to set goals, lifting their sights from the day-to-day care routines and fears.

"I am glad for their perspective," says one mother. "I was just so glad to have Peter alive. I still am sort of in a survival mode. The therapist says verbally he needs this, communication-wise he needs that. I've been thinking how glad I am that he's breathing on his own, and some of these other things I would not have picked up on. My goal is for Peter to be happy, and I am grateful for the professionals who tell me that one aspect of being happy is for him to learn to talk. And that he needs to walk. And I say, 'Oh yeah, okay...we are beyond surviving now. We are learning to walk!"

Another agrees, "I need help setting realistic but high goals at the same time. Because I had never been a parent before, I didn't even know what to expect from a normal child let alone a child with disabilities, so it was imperative to have somebody helping me see what is realistic and maybe above that, what's even obtainable maybe."

For many parents, once a disability or delay is confirmed, there is a need to achieve some kind of normalization of family life. "I think for me, our first year we were so involved with the medical community and that type of intrusion that my goal for early intervention was to minimize that intrusion. To minimize the fact that we were not living a normal life. The medical thing was just so intense and so disruptive that by the second year I really wanted everything incorporated into my daily living. I know that sounds real idealistic but it was real important for me to normalize our family in some way and to get my son to understand this world does not revolve around his schedule and that we don't sit and wait for the next person to come and help us with him. I'm just now getting to feel more comfortable with that, that he is not the first thing I think about in the morning and the last thing I think about when I go to bed. There are other children and there are other things in our life. My father made me angry once when he said, 'When are we going to get over this premie stuff?' At the time I thought 'we never will' and my whole argument is that it will be here forever. What he was trying to say is you need to normalize and he was right and our goal as a family is to do just that."

Case Management

Infants, young children, and their families require comprehensive services that are unlikely to be available through any one public or private agency. Therefore, the IFSP calls for a case manager who will be responsible for the implementation and coordination of services. The case manager is to be named "from the profession most immediately relevant to the needs of the infant or toddler and family."

In order to ensure that adequate case management is provided to the infants, young children and families to be served, each state will need to consider issues and questions related to the definition of case management, the identification of who should be the case manager, the roles and responsibilities, the training of case managers, and ensuring the accountability of case managers.

Defining Case Management. The term case management is defined differently by various agencies and individuals. An underlying assumption of all who discuss case management is that the case manager should coordinate services, put the service plan together, and make sure that the necessary people are involved. A document entitled **Focus and Functions of Case Management** (Freedman, Reiss and Pierce, 1987) defines case management as a "set of goal-oriented activities which organize, coordinate, and monitor service delivery based on measurable objectives intended to meet the needs of chronically ill Children and their families." In **A Review of Dane County's Case Management System** (Mather et al, 1982) the authors define case management as "the process of doing a comprehensive assessment of clients needs, developing an individualized service plan, providing access to the needed services, and monitoring the appropriateness and effectiveness of those services." They further indicate that the case manager is the person who is authorized by the service system to carry out or oversee those functions, to be the fixed point of responsibility, the 'unifying face.' The Division of Early Childhood (DEC) of the Council on Exceptional Children, in developing policy statements and recommendations relating to P.L. 99-457 and other federal and state early childhood policies defines case management as "the process by which early intervention services are linked and monitored in order to ensure that the early intervention needs of children and families are addressed in a systematic manner. Through case management, one person, together with the family, actively advocates for services in response to changing needs, and is responsible for implementation of an integrated program of services, in consultation with colleague specialists" (DEC, 1987).

Identifying The Case Manager. Part H of P.L. 99-457 indicates that the case manager should be an individual from the profession most immediately relevant to the infant's or toddler's or family's needs. It will be important to establish how the case manager is chosen. Will the decision be left to the parents? Will a lead agency designate someone or will there be an open discussion between family members and professionals to determine who is most appropriate?

The DEC in their policy statements and recommendations indicate that parents and a professional should be designated as co-case managers, acknowledging the roles and responsibilities of both. Parents should determine the extent and degree of their own participation as case managers to allow for differences in ability, time, comfort and interest. They further felt that the case manager should either be chosen from the agency having responsibility for the greatest portion of services in the IFSP or employed directly by the interagency councils. Regardless of where the case manager is attached, the DEC feels the choice of the individual should be with the family.

Do state licensure laws and/or certification requirements dictate who can be a case manager? Some states' practice acts say that social workers must be responsible for all case management within their borders but at this time this has not been tested relative to P.L. 99-457.

Also at issue is the question of when the case manager is identified. Should this person be determined as soon as the child is suspected of having or being at risk for developmental problems, after the evaluation of the problem but before the IFSP has been developed, during the development of the IFSP, or after the development of the IFSP? Can or should the case manager change based on changing needs of the child or family? For example, if a young child initially is noted to have a severe movement disorder but 18 months later, her speech obviously is her most significant disorder, should her case manager be changed from a physical therapist to a speech and language clinician? If so, how should this process be implemented? Also if the parents are not satisfied with the case management being done, can they request a different case manager?

To be consistent with the philosophy presented in **Family-Centered Care for Children with Special Health Care Needs** (Shelton, Jeppson, Johnson, 1987), families should have primary control over in how services are planned, provided, and coordinated or managed. The authors indicate that families, rather than agencies are in the best position to determine their needs. Professional case coordination is essential to help families determine their options so that they can make informed decisions. The authors imply that the key to decision making, in this case the determination around case management, should lie with the parents.

Case loads will be a major issue as the roles and responsibilities of case managers are being discussed. What will a reasonable case load be? This will be influenced by the state's decision either to have people who are already working with the child and family take on additional case manager duties or have case managers hired for the sole purpose of doing case management.

How Case Management Works

The following examples illustrate how the tasks of case management tie in with the service histories of families.

Local Case Manager - Foster Family. David was born with fetal alcohol syndrome to a single adolescent mother who has a history of alcohol and drug abuse. After repeated reports of abuse and neglect, the child was removed from the home and placed in foster care. The case manager in this instance sees that the child receives the assessment, treatment, and educational programming that he needs. The case manager also works with the agency that is providing supportive services to the child's mother. At this point she has no visitation rights but there is a long range goal of trying to support them as a family unit. The case manager has regular contact with the foster parents who are caring for the child at this time, and helped to work out a plan for transition when the first foster family that had David found that his behavior was too challenging for them to deal with.

Local Case Manager. A local case manager has also been assigned to Ellen, a fifteen month old child with significant developmental delays in cognitive, language, and motor functioning. Ellen is in a birth-to-three program that is part of a public school system and after evaluating her needs, an early childhood teacher agreed to be her case manager. As her case manager, the teacher is in close communication with Ellen's parents, shares information about Ellen's strengths and weaknesses, the community services that are available, the components of the IEP and how they can proceed if they feel that they are not being adequately served. When Ellen needs diagnostic or assessment services from tertiary facilities, her case manager facilitates these appointments by providing information about the school's work with Ellen, by attending the assessments with the family, by reviewing reports generated by the tertiary facility with the family, and by being available to answer questions and act as a source of emotional support to the family. When questions arise that the case manager is uncertain about, she contacts the necessary people until she gets a satisfactory answer. If all goes as planned, she will continue to act as the case manager for Ellen until she enters the school system's Early Childhood Program when she turns three years of age. This case manager will work with the family and the school around the transition to a new program.

Facility Case Management. At the request of the parents, two tertiary care facilities (a University Affiliated Program and a pediatric pulmonary center in a large university hospital) work together to provide case management for a child with a severe respiratory and central nervous system disorder. Staff from the pulmonary center approached the UAP for assistance with service coordination. Issues that revolve primarily around the child's medical management are handled by the pulmonary center while issues around schooling, connecting the family with community resources, and the provision of therapy or nursing services are managed by the UAP. This child's needs are so complicated that there is constantly a need for case management that comes from outside her local community. For the most part, local agencies have refused to work with this ventilator dependent child and her family on an ongoing basis. Six different nursing agencies have been involved in providing direct nursing care. After a period of homebound educational services, the UAP was able to get the district to permit the child to attend classes at school. At this time the mother must be in school every day to attend to the child's medical needs because all the nursing agencies have withdrawn. UAP and pulmonary center staff are in frequent contact with the mother, school, and involved community agencies.

Parents As Case Managers. When the Jones' first child was born the mother decided she would not work outside of the home while her children were young and at home needing her care. When a second child, Charles, was born, it was evident that his needs would be greater than those for the average child. He has cerebral palsy, spastic quadriplegia and visual and hearing impairments. His parents did a great deal of reading and communicating with other parents of children with disabilities and with professionals. They investigated available resources in their community and advocated for resources that they felt would be helpful to themselves or to other families with children who are disabled. They felt that were in the best position to act as case managers for their children.

Co-Case Management. An example of co-case management revolves around the needs and experiences of a young girl with Rett Syndrome and her family. When first seen at the UAP at age two, Ann's family was in a state of crisis. They were dealing with a new baby while trying to find answers to very difficult management problems around Ann's behavior. In addition to helping the family understand Ann's behavior, UAP staff started to function in the role of case manager. For the most part, a social worker did the case management, but at times he was assisted by staff from pediatrics, occupational therapy, psychology, special education and nursing and for some periods of time one of those individuals managed the case through a challenging situation. The UAP social worker gave the family information about community resources that would be available to them and helped them to prioritize which agencies should be approached and in what order. The family's most immediate needs seemed to be for a birth to three program in the early childhood program in the public schools. Staff from the UAP attended the planning meeting with the family.

As the parents became more comfortable with Ann's school program, they decided that they would like to use respite services. Staff from the UAP and the county family support agency made a joint home visit to discuss respite services and the family's needs. Again it took time and ongoing interactions for the parents to become trusting of outside agency persons.

UAP staff encouraged Ann's parent to get involved with a newly formed Rett Parent Support Group in the area. As they became involved with the activities of this group, the parents became more independent, and confident and took over more case management, using UAP staff, as well as neurologists, respite workers, public personnel, and other professionals as service providers and consultants rather than people who could or should tell them what to do.

Although their relationship with the school and service providers continues to have ups and downs, parents are able to deal with this and look for special case management assistance only rarely.

Formal System of Case Management - Arlington School District Model Case Management System. The Arlington, Washington School district serves a small, rural area in northern Washington state. Growing concern by area professionals over the lack of coordinated services to young infants and children promoted the development of a model interagency case management system. Any professional or parent can refer a family for case management, which is coordinated through the local public health department. Parental concerns, health and developmental assessment, and family resources are all considered in the system. Infants and toddlers who are "at risk," as well as infants with current health or developmental problems can participate. Professionals representing diverse services such as family child care, child protective services, nursing, and community services collaborate with the family to design an Individualized Family Plan. Services to the family are coordinated by the Case Manager. This program became a Handicapped Children's Early Education Program (HCEEP) grant recipient in 1987.

SUMMARY

The establishment of service goals and the identification of the case manager are two important steps in the process of developing the IFSP. Both these steps are ones that call for the concrete practice of parent-professional collaboration. In the next chapter issues related to the actual services needed to accomplish the outcomes will be discussed.

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CHAPTER 6

How will the needs of children and families be met?

Services

Up to this point, the group of children to be served has been identified and those children and their families have been brought into contact with the service system. There has been an evaluation where family and child needs and strengths and outcomes for services have been established through the IFSP. The IFSP then calls for an identification of the actual services required to move toward those outcomes.

This is the area that might be referred to as "the service delivery system." But given the revolution in thinking about the quality of the relationship between services and families--where families are meant to be at the helm as collaborators and partners with professionals--"service delivery" may be a poor term to use, implying passivity, a sense of being "done to." As a substitute, or at least as a modifier, parents have responded positively to the term "resources." Instead of delivering services, professionals might be seen as "making resources available," particularly where family needs, as opposed to child therapeutic needs, are involved. "Resource" originates in the root of "to rise again, to resurge" which has a strengthening quality appropriate to the spirit of the law.

"It makes parents sound resourceful; they use resources so they are resourceful," comments one parent. "It also implies a choice, that 'service delivery' seems to take away. I remember the first time I said 'no' to a service, and my home visit person said 'that's fine, that's just a resource for you to use if you want it.'"

"I think we should start with a whole other picture of early intervention services," says another parent. "With what the new law intends, with what we have in mind as parents, I don't think you can plug our children into the models that we have now. That's why people can't picture serving so many new kids. I would hate the state to say, 'Okay every child with this kind of need has to go into this program.' Everyone is in a frazzle about the law because we can't be putting babies on school busses and we don't have enough home intervention teachers to fill the needs. Well, that's not what we're talking about. We're talking about a menu of services, and it's an option for parents to say 'I don't need it. All I need is a little respite care for now, not a whole preschool program.' There has to be a multi-level of services and with the family doing the choosing, the models we have now may just be a piece."

While we will continue to use the term "service," we would like the term to have the quality of "resources." In this chapter we will be dealing with the specifics called for in the law, background on the philosophy of service intended and then some of the issues faced in developing a responsive process for "making resources available," including the balance between flexibility and consistency in services, the location of services, the choice of service providers, the role of health services in early intervention and examples of various programs.

For birth through two-year-old children, both the law and Committee Report 99-860 (U.S. House of Representatives, 1986) are notably silent about the exact nature of the early intervention services to be provided. Thus, states are left with a great deal of latitude about whether to provide home-based or center-based services, whether those services should be full-day or part-day, how frequently the services should be offered, the child-staff ratios or caseloads which should be used, and the philosophical orientation which should be followed. The law does state that early intervention services are to be based on the needs of the child and the family. But a determination of exactly how this broad statement about appropriate early intervention services should be put into practice is left to the discretion of the states.

Services mentioned include services which directly address the developmental, habilitative, or rehabilitative needs of the child, such as special instruction, speech pathology and audiology, occupational or physical therapy, psychological services, or limited medical services. In addition to these specific "child focused" services the new law outlines services to the family that can be seen as "enabling services" (Trohanis and Magrab, 1987). These are services which make it easier for families to access and utilize needed services. Enabling services include family training, counseling, home visits, identification, screening, and referral systems. One of the most potent enabling services provided under Part H is case management.

The list of services mentioned in the new law is by no means exhaustive. State planners will face additional program decisions regarding child care, legal and educational advocacy, family housing assistance, employment counseling and well child care. These services may not have previously been thought of as early intervention services.

Participation of the family of the disabled or at risk infant or toddler is critical to successful model building. P.L. 99-457 "offers opportunities for families to use their strengths on behalf of their own and other young children with disabilities. Parents can be service providers and care managers as well as service recipients. They can be trainers as well as trainees. They can help to evaluate the functioning of service programs as well as participate in the assessment of their own child and family needs. They can advise as well as be informed" (Gilkerson et al., 1987).

Planning Services

Because the service population under Part H is unique we must guard against merely modifying existing programs for other populations and watering them down to suit the needs of younger children. This approach will fail to provide the variety, number and flexibility of service options that are necessary to meet the needs of young children and their families. In addition, such an approach would preclude the opportunity to design service options to meet the individual needs of the infant and his or her family.

Two recent publications of the National Center for Clinical Infant Programs can begin to provide the needed background information for informed, guided decision making. The two publications: **Infants Can't Wait** and **Infants Can't Wait: The Numbers** (NCCIP, 1986a, b), offer information regarding the service needs of infants and toddlers across the nation. Based on this information a comprehensive plan of initiatives requiring action at the federal, state, local, public and private levels is provided. The message is clear; service delivery planners at all levels should begin to work towards the provision of a basic floor of integrated services for *all* infants and toddlers. Building on that, we should "expand comprehensive, integrated services for infants and toddlers with special health and developmental problems or Disabling Conditions and for their families" (Infants Can't Wait, 1986a). The initiatives proposed are consistent with P.L. 99-457 and can serve as a framework for state and local level planners. The recommendations of these two publications can assist the ICC's in targeting their long range efforts, and obtaining a broader perspective on the scope and range of infant toddler services. A corroborative view is given by Gilkerson et al., (1987) commenting that P.L. 99-457 "offers us an opportunity to create programs that offer children and families a coherent core of basic services. These should include, at a minimum: child development/educational services; appropriate therapies, health services; and parent support."

P.L. 99-457 and the accompanying rules and regulations provide states with flexibility in the design of a comprehensive statewide, coordinated interagency service delivery system. This will permit states to build upon service delivery systems already established, while designing and implementing new programs or developing collaboration between programs.

State systems planners might visualize the range and variety of service options to be provided as a continuum of service, initiating with early identification and screening, and encompassing multidisciplinary evaluation, preventive intervention, as well as what is regarded as comprehensive early intervention services. Fewer infants and toddlers are served at each successive level. Conceptualizing the range and variety of services in this manner promotes the idea of movement between service options as the needs of the child, or the family change over time. Not all infants will require intensive levels of service, and families abilities to participate and benefit from early intervention services will vary. This approach views intervention services as a dynamic process rather than static. Viewing the wide range of intervention services in this way allows planners to consider prevention activities as part of the statewide plan. Utilizing this framework, any existing or proposed program can be identified within the continuum.

Flexibility Versus Consistency

The lead agency and the ICC must design a model which simultaneously promotes a statewide coordinated system, yet remains flexible enough to address the unique needs of local communities. Unique circumstances, including low incidence populations such as deaf-blind infants and toddlers, or extremely remote and isolated communities require approaches to service delivery that may not be traditional. The proposed system must be able to address circumstances in a coherent and consistent fashion.

The problem of fragmented service delivery, particularly in rural areas, has become a national concern (Fraas, 1986; McPherson, 1983). States will need to explore service delivery options which will allow similar services to families regardless of their place of residence. An example of the kinds of discrepancies that may occur in service delivery is provided by county funded family support programs in one state. The actual services available to families, and access to those services, often depends on the demographic characteristics of the county. Typically, more comprehensive services are available in primarily urban counties.

"We live in a rural area," says a mother of a child with cerebral palsy. "I know the urban areas give you a different feel--you have much more. Your services are possibly the same but maybe a little better quality than what we receive in a rural area. When I hear a mom talk about play groups where children and the mothers would go in and visit... well, you don't have that in a rural area. You're on your own, and I think that makes a big difference. The issues of quality child care is an issue to us, but it's not a disability issue. In a rural area you wouldn't have enough special needs kids to fill up a special child care center. The problem is availability of child care, period. Not just special child care."

The Location of Services

The current range of alternative models of service delivery including home-based, school-based, hospital-based, and combination models, needs to be examined (McCoy et al., 1987) as each state implements early intervention programs. Each service delivery model has inherent advantages and disadvantages for children and families. For example, in many school-based models the early childhood special education teacher is in the central role as service provider. Other services, such as nursing, occupational therapy, physical therapy, or speech and language therapy, are provided on site. The advantages of the school-based model include: personnel certified certified by the state education agencies; transportation; and established programs and guidelines. Potential disadvantages are: the lack of flexibility to accommodate both the needs of the child and his/her family, limited interactions with non-handicapped peers, limited diagnostic and evaluation services, as well as other medical treatment services, and the gap in service delivery during the summer months.

Home-based models may involve an early intervention specialist, or a health-care provider trained in developmental disabilities, visiting the child at home to provide training and consultation for the parent. The advantages of a home-based model include: contact/training with the child and family in their own environment, flexibility of time and intensity in service delivery; increased contact with parents; and relatively low cost to implement and administer services. Disadvantages are inconsistency in training and experience across service providers, limited opportunities to recommend or coordinate additional services such as therapy, and limited child/family contact with other children with disabilities.

Hospital-based models are usually affiliated with perinatal centers. Advantages include: staff experience with very medically-involved children; availability of on-going screening; diagnosis and treatment; and access to health care personnel. Disadvantages may be: a lack of educational and/or social service components; limited family-based services; a need for transportation to the centers; and restricted opportunities to interact with non-handicapped peers.

Least Restrictive Environment (LRE) for Children Under 3 Years of Age

Is a school-based setting more or less restrictive than a home-based setting? What about hospitalized infants and toddlers? An argument **for** school-based early intervention systems follows from the current societal trend which indicates that many young children regularly attend group child care settings from an early age. Thus, school-based services may be more typical of the child's daily environment (depending upon the extent of integration with nonhandicapped children). In addition, for children from environmentally restricted homes (e.g., poverty level or intellectually limited parents), the experiences and opportunities available in school-based programs may facilitate developmental progress. On the other hand, many child development experts argue that the natural environment of the young child is the home. They contend that school-based services tend to be more structured than the ideal environment of very young children should probably be.

State and local level planners are encouraged to explore building partnerships with community based generic program for infants. Local community programs that can be accessed as part of the service plan for families and infants include cooperative child care, community college-sponsored parent education and child development programs, new parent support groups, and community-based recreational or educational programs for families. Incorporating generic services for families into a part of service delivery model for at risk and disabled infants and toddlers has multiple benefits. First, it increases community awareness of early intervention and sensitizes generic service providers to the needs of families with special needs children. For the infants and toddlers, enrollment in generic programs may constitute the least restrictive environment for intervention services.

Designating Providers/Agencies

What system will be established to link families to services once assessment has been completed and an IFSP has been written? What about competing programs? Programs with different philosophies? A variety of mechanisms have been suggested and/or employed to link children and families to needed service providers or agencies. McCoy, et al. (1987) reviewed the relative merits and drawbacks of several mechanisms including a voucher system, a regionalized service delivery system, and a system of shared responsibility across multiple agencies. The use of a voucher system would empower parents (as consumers) with the ability to select service providers of their choice, in addition to encouraging integrated programming and reducing bureaucracy. Potential drawbacks of the system include limited availability of service choices in rural areas, placing responsibility for choosing services on parents who may lack information, perspective, or guidance to make appropriate choices, and the potential for profiteering among competing agencies or providers.

Collaborative Services

Close collaboration between the state level agencies for health, education, and social services is critical for successful implementation of P.L. 99-457. Regardless of which agency is designated as "lead agency" for Part H all players have equal importance in planning and providing a comprehensive service delivery system. At the earliest stages of intervention it is nearly impossible to segment a "health" intervention from other interventions.

Health services play a key role in early intervention. Health service providers often have the first opportunity to observe developmental concerns in a young child. Parents most frequently approach their primary health care provider when they have questions or concerns regarding development. Many infants experiencing developmental concerns may also have ongoing health/medical conditions. In order to benefit from the provision of educationally or therapeutic directed early intervention services the health of the child must be stabilized, and monitored to ensure that the child can receive the maximum benefit from the services.

The initial assessment of an infant or toddler for services under P.L. 99-457 should include at a minimum a complete physical and neurodevelopmental evaluation, and a review of the child's medical history. Medical factors, such as ongoing medication, may influence a child's performance during the assessment phase, or might influence his individual program. Children who experience ongoing health concerns such as seizure disorders, cystic fibrosis, congenital heart disease, AIDS or recurrent otitis media are at significant developmental risk due to recurrent illness or hospitalizations. Their developmental progress must be carefully monitored. In addition, medically fragile children or children whom are dependent on technology for life support represent a growing population that will require a comprehensive collaborative approach to service provision.

The primary care physician (for families who have access to private health care) or the well child clinic nurse have a unique, ongoing role to play in the identification, management, and coordination of services for developmentally delayed at risk infants and toddlers. Dr. John F. McLaughlin, associate professor of Pediatrics, Children's Hospital and Medical Center, Seattle and interim member of

Washington state's ICC stated: "Every child who has primary care provider has a 24 hour a day, 7 day a week, source for consultation and case management. We can begin to build collaborative relationships with the health services sector by fully including health, education, and social services as full partners in the development of a statewide comprehensive plan.

The Committee on Children with Disabilities of the American Academy of Pediatrics has proposed principles of care for infants and toddlers related to P.L. 99-457 (American Academy of Pediatrics, 1987). The principles proposed support collaborative efforts between the social, educational and health service sectors to promote the role of the family in access to medical care. The role of the physician in the identification, evaluation, treatment, and monitoring phases of early identification are clearly identified. Action steps for state planning addressing practices and efficacy, parent-professional interaction, service organization, service promotion, and staff training are provided.

The guidelines proposed by the committee can provide a framework for preliminary discussions with health care providers at the state and local level. State planners should review these principles in the initial stages of program development.

"Physicians are going to have to identify these kids and head them in the right direction. So they need to be provided with the information for what services are available so that when a concern emerges, their family can be headed in the right direction," says a rural father. "But in a rural area you're going to have to go back to your home town doctor. That's the one place that everybody goes. Your children all have to have their vaccinations and their shots and you know they're going to be there and you know that's where they're going to get their information from in a rural area."

The Role of Health Services in Early Intervention

The needs of at-risk and developmentally delayed infants and toddlers and their families often cannot be met by one discipline or a single agency. The new law provides incentives for developing collaborative services across health, education, and social services. In addition to the conflicting eligibility criteria encountered among service delivery programs will be philosophical and turf issue barriers. The Interagency Coordinating Councils through their ability to develop and promote interagency agreements can begin to encourage cooperative, creative partnerships at the state, and local level in programming, as well as funding (Section 682, 5E). Interagency efforts will be discussed more fully in Chapter 9.

Blended service delivery programs which foster partnerships between agencies are an exemplary approach to appropriately serve eligible infants and toddlers. Building a concurrent services delivery model requires the active participation of **all** collaborating services. Guidelines for how to achieve such a program have been developed by the Networking and Evaluation Team at the Experimental Education Unit at the University of Washington in Seattle.

Service Effectiveness and Costs

A determination of the exact nature of early intervention services to be offered will be strongly influenced by financing. Some types of services cost more than others. The type of service offered determines the amount of money spent, and the amount of money spent has to be consistent with the amount of money available.

But how does an administrator decide what type of early intervention is most appropriate? The research literature is full of reports about the effectiveness of different approaches to early intervention. These different models provide dramatically different types of early intervention and are associated with very different price tags. For example, over the last 20 years, the Department of Education has funded "model demonstration programs" under the Handicapped Children's Early Education Program (HCEEP). Of the more than 400 such programs which have been funded, 21 were approved for national dissemination by the Joint Dissemination Review Panel (JDRP), which is an interagency panel established by the federal government in 1975 for the purpose of determining if specific educational programs have sufficient evidence of effectiveness (see Table 6.1). To justify including them in an official government publication entitled, Educational **Programs That Work**, (National Diffusion Network, 1983) each application was reviewed by at least 7 members of this interagency panel and approved for national dissemination if the panel concludes that the project has demonstrated educationally significant effects based on reliable and valid data which were obtained using well-documented and replicable procedures (Fang, 1981).

Given the rigorous evaluation to which projects submitted to the JDRP are subjected, it would appear that a great deal of useful information about what types of early intervention programs are best would be available by carefully examining the results of these projects. Indeed, Odom and Fewell (1983) concluded that JDRP projects "were among the best the field has to offer."

Table 6.1

HCEEP Projects Approved for National Dissemination by the Joint Dissemination Review Panel

Project	Primary Handicap of Children	Ages Served	Sample Size	Durantion (weeks)	Effect* Size
HOME-BASED					
Macomb 0-3 Project, Illinois	combination	0-3	34	77	.28
Peoria 0-3 Project, Illinois	combination	0-3	77	52	1.33
UNISTAPS Project, Minnesota	hearing impaired	0-5	25	39	.66
Central Institute Project, Missouri	hearing impaired	0-4	29	154	NC
DEBT Project, Texas	combination	0-2	103	65	.55
PEECH Project, Texas	combination	1/2-6	98	189	1.24
SKI*HI Project, Utah	hearing impaired	0-6	40	43	1.01
C.P. Project, Wisconsin	orthopedically impaired	0-3	36	39	NC
Portage Project, Wisconsin	combination	0-6	57	39	1.05
CENTER-BASED					
Rutland Center, Georgia	emotionally	2-8	49	22	NC
PEECH Project, Illinois	combination	3-5	37	30	.34
High Scope Project, Michigan	combination	4-6	16	39	.66
Regional Demonstration Project, NY	combination	3-5			
Chapel Hiil Project, NC	combination	4-6	90	34	.53
Good Samaritan Hospital Project	multiple handicapped	0-6	28	39	.70
Down Syndrome Project, Washington	mentally retarded	0-6	66	39	NC
COMBINATION					
Erin Project, Massachusetts	combination	2-7	25	26	.70
Preschool/Families Project, ND	combination	0-6	35	30	.44
Teaching Research Project, Oregon	combination	1-8	20	–	NC
MAPPS Project, Utah	combination	0-5	120	77	1.65
Communication Project, Washington	speech/language	0-6	39	43	2.27

*Note: Numbers in this column indicate how effective a program was based on calculation of the average difference beteen experimental and control groups divided by the standard deviation of the control group. Where NC is listed, an effect size could not be calculated.

(White et al., 1984.)

Interestingly, a careful examination of these projects demonstrates why congress did not specify the exact type of early intervention programs to be provided. As shown in Table 6.1, the projects approved for JDRP have included home-based, center-based and home and center-based programs. Some have worked with very young children, other have worked with older children. The duration of programs has varied from as little as four months to as much as four years. Home-based programs have varied from as little as one visit per month to as much as four visits per month. Center-based programs have included both half-day and full-day programs, and programs which were three days-per-week, as well as five-days-per-week. The research results submitted as a part of the JDRP approval process do not demonstrate that the programs have dramatically different results in spite of the great deal of variation in type of program offered.

There is, however, a great deal of variation in the cost of different kinds of programs. Based on work done at the Early Intervention Research Institute at Utah State University, a one-time per month, home-based program which meets all of the other guidelines contained in P.L. 99-457, can be delivered for as little as $1500 per child per year. Whereas a center-based program which provides one half-day, five days per week of services for infants and toddlers with mild and moderate disabilities would cost about $4500 per year per child. The same program for infants and toddlers with severe disabilities would cost approximately $7000 per year, and a full-day program which provides center-based services five-days-per-week, plus weekly home visits for severely handicapped children would cost approximately $12,000 per child per year. These numbers are all approximations since the exact amount would vary depending on the salaries of staff, the caseloads or adult-child ratios, and the comprehensiveness of the program. It is obvious however, that dramatically different costs are associated with different program options, and that we do not yet know which type of early intervention program is most cost-effective for which children. See Barnett and Escobar, 1987, for an excellent discussion of the literature on the economics of early intervention.

A very real danger in presenting evidence such as the proceeding, is that an unimaginative administrator may jump to the worst possible conclusion: "Since you get about the same effects with different models of intervention, let's use the cheapest one." Such a conclusion is tempting administratively because it is much easier to manage a state program if everybody in the state uses the same model with one set of guidelines and rules and uniform monitoring and reimbursement procedures. Such a "one-size-fits-all" philosophy is not only wrong-headed and short-sighted, it could have devastatingly negative consequences for the outcomes of early intervention programs since it ignores the following information:

- Children and families are different and consequently have different needs and will respond differently to programs.
- It may be that neither the cheapest nor the most effective program is the most cost-effective.
- Although many models of early intervention have been promoted, we do not yet have sufficient research data to make decisions about which model is most effective for which children.

The proper interpretation for the foregoing information is extremely important as we consider the financing of early intervention programs. Namely, the development of statewide systems of early intervention must be done in such a way that the effects and costs of different types of services can be carefully evaluated. The need for such systematic variation is emphasized by the fact that funds for early intervention are limited. Administrators know that if they spend $15,000 per child per year on a particular type of early intervention model instead of $3000 per year for a different early intervention model, it could mean that four children will be excluded from receiving early intervention. Before such decisions are made, we need much better information about the relative effectiveness of alternative types of early intervention programs.

How can future research studies move closer to providing this information? Guralnick and Bennett (1987) suggest that one major weakness in efficacy research to date has been a failure to carefully define the research population. The diversity of characteristics in the group of children involved in early intervention services and the need for interventions scaled to those diverse characteristics makes this critical. Another complementary need is for more detailed descriptions of the early intervention efforts themselves. To accomplish both these refinements so that results can be shared between programs and studies would be a major step toward improving the quality of the information that comes from early intervention research.

Program Descriptions

A complete descriptive catalogue of programs is not possible, but we offer here a description of some programs connected with University Affiliated Programs (UAPs) that were designed to meet particular state needs.

Community Collaborative Projects: Child Development Center - New Orleans. The University of Affiliated Program at the Human Development Center, Louisiana

State University, New Orleans, has developed two model programs utilizing community-based service providers. The purpose of the project is to develop and implement inservice training with community-based generic service providers to improve their ability to work with disadvantaged infants at extreme biological risk. Both Kingsley House, a large federal housing project, and the Greater New Orleans Urban League had a history of providing parent support, parent education, and child development services to normal infants. The target service population of the community service programs is inner city, poor, minority parents. Due to the unique demographics of the New Orleans area a predominance of teen, single parent black mothers are enrolled in the programs. Infants identified for the collaborative program are identified at birth as biologically at risk, and eligible for early intervention services. In both the Kingsley House and the Urban League programs, project staff work collaboratively with existing personnel to develop and implement appropriate home and center-based programs for the infants enrolled. A case manager from the project monitors each child's program and supervises project staff. The collaborative process, providing technical assistance and guidance has fostered a model for integrating disabled/at risk infant into community-based programs which previously only served non-disabled populations. Dr. Robert Crow, Director of the Child Development Center offers several key points to consider when planning collaborative efforts with community agencies. First, when working with minority agencies, the ownership of the program rests with the agency, the role of the UAP is to support the agency by providing "cutting edge" guidance and technical assistance rather than direct service. Furthermore, the goal with community-based intervention is to develop personnel who can facilitate families using an ecological model, rather than providing recipes for intervention.

Very Early Intervention. The earliest interventions may begin before the at risk infant has even left the hospital. Infants that are at extreme biological risk due to factors such as extreme prematurity, low birthweight, or intraventricular hemorrhage may receive developmental interventions in the Neonatal Intensive Care Unit Nursery (NICU). Developmental interventions are designed to assist the developing infant to integrate autonomic functions, increase motor control, and integrate transitions between states of consciousness. The goal of developmental interventions with the very sick infant is *not* to focus on the achievement of developmental milestones or to offer stimulation to foster developmental skills appropriate for full-term infants (VandenBerg, 1985). As more infants are served in the NICU, the role of developmental interventions in both the unit and after discharge will become a more important component of early intervention.

In Neonatal Intensive Care Units across the country programs assisting the youngest, and sickest infants are underway. These programs require the careful integration of hospital nursing professionals, physicians, and family members.

At Georgetown University Hospital two programs are currently conducted collaboratively with the Georgetown University Affiliated Program. Model programs have also addressed the needs of NICU graduates as they prepare to leave the hospital, and during the transition home. At Charity Hospital, in New Orleans, the second largest public hospital in the country, staff nurses have received inservice training to assist families in developing discharge care plans. This model program, coordinated by the Louisiana State University UAP recognizes, and builds upon the unique role of the primary care nurse. Families whose infants remain in the NICU over several weeks or months often develop close and trusting relationships with nursing professionals caring for their child. Families often seek the advice of the nursing staff in planning for discharge. Issues such as home medical care, safety, and access to services can be better coordinated and facilitated through this informal discharge process.

Other programs, such as the Transactional Family Systems Model Program support the family after the NICU graduate has returned home. The goal of the program is to train parents to become sensitive to their infant's subtle and often confusing communication cues. Rodd Hedlund, coordinator of the model program located at the University of Washington UAP states the goal of the program is "to instill in the parents a sense of competence while assisting them to see their child, regardless of handicap or medical condition, as a competent, growing, individual."

Based at the University of Washington UAP, the Early Childhood Home Instruction Program for Young Hearing Impaired Children and Their Families has been providing very early intervention services to families in the western Washington area for nearly fifteen years. Under the direction of Marie Thompson, Ph.D., Professor of Special Education, at the University of Washington, hearing impaired infants and their families receive weekly home visits from masters prepared professionals from the fields of deaf education, speech pathology or audiology.

Home visits are scheduled to include siblings, grandparents, or other family members. Special efforts are made to include fathers, such as scheduling evening visits. Home visits are a family affair--where all family members can receive information, and obtain guidance in how to work with their hearing impaired family member.

Infants who have bilateral sensorinerual hearing losses greater than 20 db are eligible for services through the program. The program serves infants and toddlers to age 3. The home visit curriculum contains information regarding the auditory system, hearing aids, auditory training, communication, and language development. At each home visit, parents are given support, direction, and assistance to integrate the weekly lessons into the family's routine. Parents are partners in interventions with their children, as well as in ongoing assessments to monitor the child's individual growth and development. In addition to the weekly home visits, parents can also choose to participate in a twice weekly classroom group experience offered at the Experimental Education Unit at the University of Washington. Parents meet as a group during the classroom sessions to hear guest speakers, improve sign language skills, or just share experiences. Additional professionals include an audiologist and counselor, trained to work with families of hearing impaired children is also available to families in the program. Sign language books, and videotapes are also offered to parents through a lending library.

Serving low incidence populations is a challenge due to the large distances that parents and professionals often have to travel to access or provide services. The ECHI model has successfully served families in outlying areas by utilizing existing professionals, use of the videotape library, and occasional visits to the "home campus" at the University of Washington. Hearing impaired infants and their families can receive specialized instruction and support through the program, and still participate in child care, preschool, or other community based activities.

Multicultural Training of Trainers Project. Dr. Samuel Chan of Children's Hospital of Los Angeles described the (MTOT) project as a new twist on an old theme. The concept of training community members to be trainers themselves is a technique which has proven successful. The MTOT took the model one step further. Targeting minority group parents of special need children from birth-21 for community training was the focus of the two-year project funded by OSERS as part of the legislative effort to establish parent training and information centers.

Parent trainers, selected from the community and supported by a team of professionals, organized community based parent programs. Each parent trainer organized 5-10 monthly workshops for special needs parents. Topics included advocacy, resources, transition services, legal issues, as well as child development. Parents participated in the two year project from the greater San Francisco Bay area, San Diego, and Los Angeles representing a wide variety of minorities: Korean, Chinese, Vietnamese, Hispanic and Black Americans. Dr. Chan summarized the benefits of the project as primarily enhancing the number of community resource people, increasing the number of bilingual community leaders, and reaching out and engaging special needs parents who previously have not had access to parent support/advocacy groups. When funding for the MTOT was not renewed, it was noted that many of the parent groups transitioned to more generic parent or community groups, a strong statement of the impact of this approach. Special efforts to reach ethnic and culturally diverse families and their children will be required to fully implement the new law. Minority parents often cannot access services through traditional channels. Each state must carefully review the cultural and ethnic diversity of it's population, and plan outreach activities accordingly.

PKU Clinic - University of Washington. The PKU follow up clinic enjoys one of the best national records for control of this hereditary disease. PKU is a disorder in which the liver enzyme phenylalanine hydroxylase is inactive. This enzyme converts the essential amino acid phenylalanine to tyrosine. When this reaction is blocked, phenylalanine accumulates in the blood. Prolonged elevations result in severe, irreversible neurological damage. PKU is an established risk condition which affects approximately 1 in 14,000 live births. It is predominant in the white population.

Newborn metabolic screening programs identify newborn infants with PKU for prompt initiation of treatment in the first days and weeks of life. The long term treatment for PKU involves a carefully monitored, restricted diet to maintain low blood levels of phenylalanine (Trahms, 1986).

The PKU Clinic currently serves sixty children in Washington state ranging from newborns to 20 years of age. Cristine Trahms, PKU Clinic nutritionist, attributes the success of the clinic to several key factors in the clinic's ongoing program.

- All bloodwork is handled in a single state run laboratory, ensuring consistency and a high level of quality control.
- An immediate diagnostic work-up of PKU infant occurs during confirmation of PKU. The PKU team, which includes nutrition, nursing, social work, and medicine, meets with all members of the family during this period of initial diagnosis.
- Genetic information and treatment plans are shared with the family immediately. The professionals clearly convey that the management of PKU involves lifetime nutritional management.
- Parents are partners in the ongoing management of their child's condition.
- Contact with the PKU team is ongoing. A home visit occurs soon after hospital discharge. Families return to the clinic monthly for ongoing support and blood level monitoring.

These components have brought national recognition to the staff and families involved in the PKU Clinic at the University of Washington.

Preventive intervention at its best minimizes the stress on the family while supporting the development of the infant and toddler. In the management of PKU, if nutritional support occurs early on, early intervention services to address developmental disabilities will not be necessary. Cris Trahms states, "If a condition is important enough to have legislated newborn screening, it is ethically obligatory to provide follow-up."

SUMMARY

In summary then, what do we know about what quality early intervention services for the child should be like? We know that family decision-making and collaboration in services will be critical, and that the services for the child need to be based on the specific strengths and needs of that child. According to Guralnick and Bennett (1987) the intervention should "ensure that developmental processes and relationships closely approximate those compatible with the principles of normal child development and sound family and community functioning...Anyone observing a good comprehensive early intervention program is likely to find a highly stimulating, responsive but organized environment that contains an array of curricula and materials all sensitively tuned to each child's needs. Even though some of the intervention techniques may appear to violate normal developmental patterns, such as when substitute methods for communication are used, these efforts are nevertheless designed so that child either remains or is restored to a path compatible with general developmental principles and processes."

If the needs of children and families identified in the IFSP are to be met in this individualized fashion, it is clear that states will need to take a fresh look at what service means, what the range of service options might be under each family and child need and how these options balance with financial resources. More information on the effectiveness of various service options is clearly needed in order to do this but creativity--the ability to see new and flexible ways to provide resources to families and children--will also be critical. In the next chapter, issues involved in financing services will be discussed.

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CHAPTER 7

How will the needs of children and families be met?

Financing services

Public Law 99-457 makes appropriate early intervention services available for 3-5 year-old children with disabilities through a downward extension of P.L. 94-142, and for 0-2-year-old children by the creation of a new state grant program. Because the new law is both an extension of existing statute, and the creation of a new state grant program, there are similarities and differences between what has been required under P.L. 94-142 and what will be required under P.L. 99-457. The similarities may create a false sense of security for administrators until they realize the monumental challenges associated with developing and financing early intervention programs for very young handicapped children. The most successful approach to financing of early intervention programs will require a fresh perspective, creative planning, and substantial new initiatives and effort.

This chapter will summarize the provisions of the statute which govern the financing of early intervention programs under P.L. 99-457, outline some of the major challenges associated with financing early intervention and suggest some possible approaches for meeting these challenges. Examples and resources for further information will also be offered.

Financing Under P.L. 99-457: What The Law Says

The major provisions of P.L. 99-457 (the Education of the Handicapped Act Amendments of 1986) are those which allocate federal money to fund the creation of a new state grant program for handicapped infants and toddlers (referred to as Part H) and the downward extension of the guidelines contained in Part B to provide a free and appropriate public education to handicapped children, ages three to five (section 619 of EHA).

Federal Funding Available For 3-5 Year Olds. Section 619 extends provisions contained in Part B of the Education of the Handicapped Act for school-age children 3-5 year olds. Except in a few places where specific exceptions were made, all of the guidelines which have governed the delivery of special education and related services to school-age children will now be applied to programs for 3- to 5-year-old children.

The allocation of federal monies for 3- to 5-year-old children is accomplished in three complementary ways. First, the statute authorizes:

- $300 per child with FY87 funds (Funds become available in the summer of the year mentioned, but are not really spent on programs until the following school year.)
- $400 per child with FY88 funds
- $500 per child with FY89 funds
- $1000 per child with FY90 funds thereafter.

The amount of money is based on the actual number of children a state anticipates serving during the coming year. If the state's projections are incorrect, an adjustment in the allocated funds (either up or down) will be made the following year. These amounts are the authorized amounts, and not necessarily the amounts which will be appropriated in any given year.

Second, 3- to 5-year-old children who generate P.L. 99-457 money can also be counted for funding under the regular Part B allocation of EHA. In FY87, this was approximately $340 per child. Thus, each eligible 3- to 5-year-old child will generate $640 federal funding in FY87. Depending on the model of service delivery selected, this constitutes anywhere from 4% to 40% of the cost of delivering services. For example, based on the Congressional Budget Office's estimated annual cost of early intervention, $640 represents approximately 10% of the cost (see Barnett, 1988, for a discussion of the CBO estimates).

In addition to the money received for each child served, up until 1990-91 states will receive "bonus money" for serving more 3- 5-year-old children in a given year than were served in the previous year. The exact amount of this bonus fluctuates from year to year. It is calculated by taking the total pool of money available for 3- 5-year-old children during a given year (e.g., in FY87 this amount was $180 million), subtracting from that pool the money allocated on the "per-child count" basis referred to above, and then dividing the remaining money by the number of "additional children served" in that year. For example, in FY87, $180 million was available. States reported that they served 265,814 during 1986-87 and based on their June 1, 1987 projections, anticipated serving 30,466 additional children during 1987-88. The 265,814 children generated $300 per child for a total of about $80 million. This left approximately $100 million of appropriated money which, when divided by the 30,466 new children, resulted in approximately $3200 in bonus money per child.

The law states that bonus money can be as much as $3,800 per child, but the exact amount depends on the appropriation for that year, the total number of children served, and the number of those children who are "new." Each year, the base used to determine how many children will be considered bonus children for the next year becomes the number of children served by the state in the previous year. To continue generating "bonus" children, a state would have to continually increase the total number of 3-5-year-old children served in the state.

In summary, the federal money generated for 3- 5-year-old children is based on three different mechanisms. First, each child served generates P.L. 99-457 money. Authorized amounts for this range from $300 per child in FY87, to $1,000 per child in FY90 and thereafter. Second, states can count 3- 5-year-old children to generate money under Part B of EHA (this was about $340 per child per year in FY87). Third, states are provided with an unspecified amount of "bonus" money for serving more children one year then they served the previous year. The "bonus" provision remains in effect through 1990 and can go up to $3,800 per child depending on the money appropriated in any given year, and the number of new children served nationwide.

All of the numbers referred to above are authorized as opposed to appropriated amounts. Money for FY87 did reach authorized limits even though the amount of bonus money available was only about $3,200 per child instead of $3,800 per child because of the total number of children served and the number of additional children identified. The appropriated amounts for FY88 will likely be substantially less than anticipated full funding levels for FY88 ($200 million versus $250 million).

Federal Funding Available For 0-2 Year-Olds. The allocation of federal funds to states for 0- 2-year-old children is much simpler. In FY87, $50 million was authorized to be allocated to all participating states in direct proportion to the percentage of all the nation's 0- 2-year-olds who lived in that state. In other words, since Arkansas had approximately 1% of the nation's total population of 0-2-year-old children, Arkansas received approximately 1% of the total amount of federal funds for Part H programs. Percentages were not exactly in line with the proportion of children, because under law, all states were guaranteed a minimum of .5% of the funds even if they had fewer children. One percent was set aside for U.S. Territories, and 1.25% was set aside for the Bureau of Indian Affairs.

A major difference for 0- 2-year-olds compared to 3- 5-year-olds is that federal funding is allocated based on census count, rather than the number of children served. In other words, the amount of money received, depended on the proportion of 0- 2-year-old children residing in the state, and on the number of participating states. If only half the states had chosen to participate, participating states would have received approximately twice as much money. In fact, all states chose to participate.

How much money is available under Part H? Assume all states were to provide early intervention services to 2% of their 0-2 population, and also assume that all of the Part H monies were expended in direct services (an obviously impossible scenario in FY87). Under these assumptions, the total amount of federal funding per child would be approximately $240 per child. If only 1% of the children were served, it would be approximately $480 per child.

In FY88, $75 million were authorized, and in FY89 and beyond, Congress authorized "such sums as necessary." Actual federal appropriations did reach $50 million in FY87, but appropriations in FY88 will only be about $67 million instead of the authorized level of $75 million.

Provisions Governing The Expenditure Of Money For Early Intervention Programs

As is the case with many federal funding programs, a "carrot and stick approach" is used with P.L. 99-457. The "carrot" is the availability of extra money, the "stick" is that money has to be spent according to certain rules, and in some cases, sanctions or penalties are assessed. The major rules or conditions of spending associated with P.L. 99-457 follow.

Money Must Be Used As The "Payor Of Last Resort. P.L. 99-457 funds are to be used to **supplement**, not **supplant** existing funding. These funds are to be used to expand and improve existing programs, not take over payment for programs that are already supported by states. As noted in Committee Report #99-860:

> "It is the intent of Congress that the enactment of this legislation should not be construed as license to any agency...to withdraw funding for services that currently are, or would be made available, to handicapped infants and toddlers, but for the existence of this legislation...Thus, it is our intent that other funding sources continue; that there be greater coordination among agencies regarding the payment of costs; and that funds made available under Part H be used only for direct services for handicapped infants and toddlers that are not otherwise provided from other public or private sources and to expand and improve on services that are not otherwise available" (p. 15).

The committee report goes on to make it clear that the resources from other federal programs such as Title V (Crippled Children's Services and Maternal and Child Health block grant money), and Medicaid (particularly the Early and Periodic Screening, and Diagnosis and Treatment Program --EPSDT) are to be used to support early intervention programs before P.L. 99-457 money is expended. As the "payor of last resort" P.L. 99-457 is to be used to *expand and improve existing programs*, not as replacement funding for existing programs.

The way in which the "supplement not supplant" provision affects states depends largely on how active those states have been in providing early intervention services. A state which has worked hard to create and fund early intervention programs may have a more difficult time maintaining the current level of services necessary to satisfy this provision than a state which has done relatively little in the past.

State Plans And Systems For Deliverying Services. Both Part H and Section 619 require states to develop a systematic and coordinated plan for providing early intervention services. Although described somewhat differently (in Part H, 14 requirements for a "statewide system" are described, while Section 619 specifies only that the state must have an approved state plan), the intent in both cases is to require states to delineate specific procedures to be used in organizing multi-agency services and guidelines for how those services will be financed and administered. In both cases, states must delineate how such things as interagency agreements will be developed, how eligibility for the programs will be determined, how the rights of children and parents will be protected, how individualized service plans (referred to as Individualized Family Service Plans [IFSPs] in Part H and Individualized Education Plans [IEPs] in Section 619) will be developed and used to assure appropriate services, and how availability of appropriately trained service providers will be assured. All of these provisions have direct implications for the financing of early intervention programs.

Use Of Funds. Under both Part H and Section 619, federal funds can be used to provide direct services, or to plan and develop early intervention services that are not otherwise available. For 3- 5-year-old children, the statute specifies that at least 70% of the money (75% in FY88 and after) must be distributed to local educational agencies, while only 25% of the money (20% in FY88 and after) can be retained at the state level for the planning and development of a comprehensive delivery system. Up to 5% of the money may be used for administrative expenses related to the program.

The intent is clearly that most of the federal money for 3-5 year olds will be used to provide direct services to children. Since fewer programs exist for 0-2 year old children, there is more leeway for states to use that money during these early years for planning and program development, rather than direct services. There is, however, a clear recognition by Congress that some expenditure of money for planning and program development will also be necessary for the 3-5 year old children.

Sanctions

Congress hoped that the "carrot" of additional money would be sufficient to motivate states to develop early intervention programs for all handicapped children. For 3- 5-year-olds, Congress also used the "stick approach" to further motivate states. If a state fails to provide services to all handicapped children by 1990-91, certain sanctions will be applied. (The statute extends this deadline to 1991-92 in the event that congressional appropriations do not meet specified levels.) First states will not be eligible for the money to be allocated under Section 619. Second, states will not be able to count 3- 5-year-old children in their Part B count. Third, states will not be eligible for any discretionary grant money which relates exclusively to programs, projects, and activities for 3-5-year-old children. For example, states would not be able to apply for personnel preparation money or demonstration program money which was used exclusively for 3-5 year old children.

Free And Appropriate Early Intervention

Special educators are very familiar with what has come to be know as FAPE (Free and Appropriate Public Education). This acronym is used to describe the requirement that all children be provided with appropriate services at no cost to their families. Because Section 619 is a downward extension of Part B of EHA, the provisions of FAPE also apply to 3-5 year old children. This means that all conditions governing programs for school-age children (e.g., transportation services, nondiscriminatory assessment, procedural safeguards, least restrictive environment, provision of appropriate related services) also apply to programs for 3 -5-year-old children.

In creating P.L. 99-457, however, Congress also created some amendments to P.L. 94-142. The amendments clarified a number of issues to ensure that education agencies were not required to bear the financial burden for services that were shared by other social service agencies prior to the enactment of P.L. 99-142. These clarifying amendments (NASDSE, 1986) did four things:

1. Clarified that this law did not limit the responsibility of noneducation agencies for paying for some or all of the costs of services specified in a handicapped child's IEP (20 U.S.C. 1412(6)).
2. Stated that EHA funds would not be used to pay for services that would have been paid for by health or other agencies if it were not for the fact that such services were included in the child's IEP (20 U.S.C. 1413(a)(9)(B)).
3. Clarified that the passage of EHA does not permit a state to reduce assistance or alter eligibility under Title V (Maternal and Child Health block grant, or Crippled Children's Services) and Title XIX (Medicaid) as it relates to providing services to handicapped children (20 U.S.C. 1413(e)).
4. Required education and other "appropriate agencies" to define respective financial responsibilities as a part of interagency agreements (20 U.S.C. 1412(a)(13)).

Thus, even though the provision of early intervention services must be consistent with the requirements of FAPE, P.L. 99-457 substantially clarified the way in which Congress expected FAPE to be implemented. That clarification is substantially different from current practice in many states--particularly with regard to the use of Medicaid and the sharing of the financial burden between education and other appropriate agencies.

Although the term, "free and appropriate public education" is not used in describing services for 0- to 2-year-old children, similar provisions are included. The law states that such services are to be "provided under public supervision" and are to be "provided at no cost except where federal or state law provides for a system of payments by families including a schedule of sliding fees."

The phrase concerning a "schedule of sliding fees," is different from anything contained in P.L. 94-142, and the exact interpretation is as yet unclear. The committee report offers no additional guidance but the floor statement of Congressmen Williams, the primary sponsor of the House of Representatives Bill which later was enacted as P.L. 99-457, suggests that the intent was that P.L. 99-457 would not interfere with existing schedules of sliding fees such as those used in many states for Crippled Children Services, now called by other names such as Services for Children with Special Health Needs, or Children's Coordinated Services (Title V). It is apparently not the intent that new systems of sliding fees or payments by families would be created to help offset the costs of providing early intervention services to 0- to 2-year-old handicapped children. The statute is not completely clear on this issue, and clarification is needed.

Part H also includes provisions similar to the clarifying amendments added to EHA for 3-5-year-old children. Specifically, as a part of developing a statewide system, states must demonstrate:

- The development of interagency agreements that "define the financial responsibility of each agency for paying for early intervention services."

- That Part H funds will not be used to "satisfy a financial commitment for services which would have been paid for from another public or private source" if the law had not been enacted.

- That they will not "reduce medical or other assistance available, or to alter eligibility under Title V of the Social Security Act (relating to Medicaid for handicapped infants and toddlers)."

Issues And Options

All major decisions related to P.L. 99-457 regarding the frequency, duration, and nature of services to be provided, the recruitment and retention of qualified personnel, and the administrative mechanisms necessary for interagency cooperation and participation will be influenced by the issues of financing.

It is inevitable that comparisons will be made to the experiences associated with the implementation of P.L. 94-142. It is important to remember that the development of early intervention programs will be substantially different than the experience associated with the development of programs under P.L. 94-142.

- P.L. 94-142 was superimposed on an existing public education system in which special education programs were already operational. For the majority of states, P.L. 99-457 creates a new system. The financial implications of creating a new system are staggering.

- Although it encouraged interagency cooperation, P.L. 94-142 is generally viewed as an education law, whereas P.L. 99-457 is clearly an interagency law. Traditional practice in almost all states has made education solely responsible for financing programs for handicapped children.

- Whereas P.L. 94-142 is primarily a "child-centered" law, P.L. 99-457 (particularly for 0-2 year olds) is a "family-centered" law. Providing services to families will often be more expensive than providing services only to children.

Realizing the similarities and the differences with past funding programs establishes a context for considering some of the particular challenges associated with financing early intervention programs for 0-5-year-old children. These challenges include:

- **Estimating the amount of available money.** Because early intervention services are to be funded from a variety of state, federal, and private sources, estimating revenues will be a complex task.

- **Coordinating interagency services.** Education, health, and social service agencies are all expected to participate in early intervention programs. The challenges associated with securing legitimate cooperation and meaningful participation from different agencies is another challenging task.

- **Deciding how to spend the money**. Although P.L. 99-457 provides general guidelines, a great deal of discretion is left to the states. How states decide to use the money has implications for both the short and the long-term success of the program.

State and local directors of health, education, and social service programs have a common first question about early intervention. "How much money will be available to provide these services?" The law requires early intervention programs to be funded from a variety of sources. Although the exact mix of funding sources will vary from locality to locality, every state program administrator should consider all the following sources.

- **Federal funding through P.L. 99-457**. Although this source has received the most attention, it will probably constitute a relatively small proportion of the available money.
- **State and local appropriations**. In the same way that state and local revenues provide most of the financial support for school-age programs for children with disabilities, such revenues will also provide the bulk of the support for early intervention programs.
- **Use of existing services**. Over the years, a variety of local and federal programs have been developed to provide services relevant to early intervention for children with disabilities. The law requires states to continue using these programs.
- **Medicaid funding**. The use the Medicaid funding to providing health related services to eligible children and their families is a particularly important source of potential support for early intervention.
- **Private insurance coverage**. Many private health insurance policies cover services which are required as a part of early intervention programs. To the degree that such coverage can be accessed at "no cost" to the family, it represents another source of potential funding.
- **Sliding fee scales for 0-2 year old children**. As noted earlier, the potential also exists for generating money via sliding fee scales for children enrolled in 0-2 year old programs.

A discussion of each of these funding sources follows.

Federal Funding. Even if federal appropriations reach the authorized limits referred to earlier, federal money will still constitute a relatively small proportion of the funding necessary to operate most early intervention programs. The real question in the minds of most administrators however, is whether federal appropriations will ever attain the authorized limits.

One cannot blame state officials for being skeptical. Under P.L. 94-142, Congress authorized funds for 40% of the excess costs required to serve handicapped children. Unfortunately, the largest amount ever appropriated was only 12% of the excess costs, and the current amount is only about 8%. Under P.L. 99-457, appropriations for FY87 reached full authorization levels, but funding for FY88 will be 10-15% less than the authorized amounts. Thus, there is an understandable reluctance on the part of state administrators to rely too heavily on projected federal funding.

Another concern for some state administrators has to do with the "bonus money" available for 3-5 year old children. The amount of money available in FY87 for each bonus child is substantial, four or five times the amount that is generated by each child on the "per child served" basis. Since it is one-year funding, however, states must plan for how they will make up the difference when the bonus money is no longer available.

Some administrators are also concerned about the problems associated with projecting the number of children to be served. If projections are too high, states will have to repay money to the federal government the next year. Because of this, some states intentionally underestimated the number of children to be served with the knowledge that the money associated with children who are not counted in one year can be obtained on a make-up basis the following year.

Although the federal appropriations under P.L. 99-457 make up a relatively small proportion of the total funding needed for early intervention programs, it is important to realize the advantages that such money provides. Federal money can be used to do things for which it is difficult to use state money such as program planning, personnel preparation, research and demonstration programs. The federal money can also be used to leverage state money. It other words, state legislators may be more willing to appropriate state money if they know that money will be matched to some degree by federal money.

State Appropriated Funding. The majority of the funding for early intervention programs will continue to come from state resources. In most states, this will require additional appropriations since less than 10 states were mandating early intervention services for all handicapped children prior to the enactment of P.L. 99-457. How receptive will state legislators be to additional appropriations? Certainly the availability of additional federal funding will help as will the message the federal government is sending with the passage of P.L. 99-457. Nonetheless, convincing most state legislators to appropriate additional funding will not be easy, and administrators of early intervention programs will have to devote substantial effort to obtaining support for such appropriations.

As important as the securing of additional state appropriations will be for most states, it is equally important to make sure that existing state funded services are not discontinued as a result of the enactment of P.L. 99-457. For example, many states provide mental health services to families, at least some early intervention services to subgroups of the eligible population, and other therapeutic or support services. Not only does P.L. 99-457 state that such services must be continued if the state receives federal money for early intervention, but it is essential for the success of early intervention programs in the state to make sure that such state agencies do not lose interest and withdraw their support when the federally mandated program is initiated.

To the degree that such interagency collaboration can be accomplished, the securing of state funds will also be easier because of the "united front" presented by multiple agencies. If early intervention becomes the responsibility of a single agency, the probability of obtaining additional state funds will be reduced and the successful implementation of a comprehensive system of early intervention will be threatened. State funding is critical to the success of P.L. 99-457, and administrators cannot ignore the need for systematic work with the state legislature.

Coordination And Use Of Existing Resources. Many other state and federally funded programs provide services that are appropriate for inclusion in the state's comprehensive system for early intervention. A major challenge in financing early intervention programs is to coordinate the many different available services and to make sure that they are reaching the children with disabilities and their families who are most in need. If existing services are used well, new resources can be used to serve more children or to enhance the quality of services provided.

State funded programs that are relevant to the provision of early intervention services will vary dramatically from state to state. However, a number of federally funded programs should be considered as a part of the comprehensive system of early intervention developed for 0-2 year old children and 3-5 year old children. Among those that seem most relevant, are the following:

- The Head Start program requires that 10% of its enrollees be handicapped children.
- Given the amount of discretion which states have over how they spend their Maternal and Child Health Block Grant Funds, portions of this money could be used to support early intervention.

- Every state operates a program as part of its Title V program under Maternal and Child Health. These were once known as Crippled Children's Services although many programs have different names now.

- Chapter I compensatory education programs allow for early childhood services as well as school-age services.

- Every state receives funding under P.L. 80-313, which can be used to support early intervention programs.

- Each state receives funding through the Administration on Developmental Disabilities to operate a state council which administrates discretionary grant programs. Such grants could involve support for early intervention services.

- Title XX Block Grant money is available in every state and could be used for early intervention.

- Most states have a University Affiliated Program funded by the Administration of Developmental Disabilities or by Maternal and Child Health Services. These programs offer evaluation and diagnostic services for infants and young children, but also can assist in the planning and evaluation of care plans for children with particularly complex health, educational and social needs.

- The Special Supplemental Food Program for Women, Infants and children (often referred to as the WIC program), may be relevant to the needs of some children receiving early intervention services.

- Medicaid funding which is discussed in more detail below, can be used to support some early intervention services for eligible children.

- The Childhood Immunization Program helps states and localities to establish and maintain immunization programs for the control of vaccine-preventable childhood diseases.

The challenge in involving both state and federal programs in the provision of early intervention services is to coordinate the provision of services in such a way that more money is saved in direct service costs than is expended in the coordination effort. Given the fragmented nature of services for children and families, this will not be easy. Nevertheless, the potential benefits to children and their families makes the efforts well worthwhile.

Use Of Medicaid Funding. Medicaid provides health care financing for about half of all low income children in the United States. During 1985, almost 11 million children received Medicaid benefits, and many of these benefits are similar to services provided as part of early intervention programs. Several states are already making extensive use of Medicaid to support early intervention programs.

If the use of Medicaid funding has so much potential for early intervention why isn't it used more frequently? Administrators in many states have been under the impression that the federal Medicaid program would disallow the spending of

Medicaid money to provide services which were listed on a child's IEP or IFSP. Based on the language of P.L. 99-457, however, this is clearly not the case. Furthermore, in a related court case in 1987, the U.S. Court of Appeals for the First Circuit upheld Massachusetts's use of Medicaid funds to pay for related and habilitative services for mentally retarded persons in intermediate care facilities. This case has now been appealed to the Supreme Court which has agreed to hear it. In addition, Congress is considering legislation (S. 1673 and HR. 3454) that would amend Title XIX to further clarify that Medicaid money should be used to pay for Medicaid eligible services which are part of an appropriate special education program for preschool or school-age children. Finally, several states have been using Medicaid money for a number of years to fund early intervention programs. For example, Medicaid money is currently used in Massachusetts to fund approximately 25% of the total 0-2 year old early intervention program.

All of the proceeding factors suggest that state and local administrators should carefully consider the availability of Medicaid money for supporting early intervention programs. The use of such money will only be possible for Medicaid eligible children (the exact definition and criteria are different from state to state but the majority are based on an index of low income) and can only be used for Medicaid eligible services.

The exact services which can be paid for with Medicaid funds vary from state to state as a function of the state's Medicaid plan. In most cases, however, services such as physical therapy, occupational therapy, and speech therapy are covered. Furthermore, a new Medicaid option for case management covers exactly the type of coordination activities which are essential in securing the appropriate provision of services from different agencies.

Probably the most important Medicaid service for early intervention programs is the Early and Periodic Screening Diagnosis and Treatment (EPSDT) program which is mandated in every state. EPSDT includes screening and diagnostic services to determine physical or mental disabilities as well as health care treatment and other measures to correct or ameliorate any conditions discovered.

The potential for EPSDT in helping to support early intervention programs for Medicaid eligible children is underscored by the fact that any "needs" discovered as a part of any EPSDT examination will also be covered by Medicaid funding. By using EPSDT as an integral part of the child find and diagnosis components of the Part H program, states would be able to substantially expand the use of Medicaid funding to cover early intervention services. Furthermore, as children enrolled in the Part H program "graduate" into the 3-5 year old program, Medicaid funding could continue to be used to support those services identified as "needs" as a result of EPSDT activities.

The most efficient and comprehensive use of EPSDT for this purpose will require that the assessment procedures for EPSDT be consistent with the needs and requirements of P.L. 99-457 in terms of eligibility, determination, and IFSP development. Furthermore, there will need to be much closer coordination between health and education agencies and the covered services under EPSDT will have to be structured as broadly as possible. However, by expanding coverage policies under EPSDT rather than under the Medicaid program as a whole, states would be able to offer additional benefits to just the child population. An excellent analysis of the EPSDT program and the potential for substantially expanding its impact on providing early intervention services to handicapped children is offered by Fox and Yoshpe (1987).

Private Health Insurance. Particularly as it pertains to the reimbursement for health related early intervention services, P.L. 99-457 makes it clear that payment is to be sought from private health insurance, Medicaid, the MCH block grant program, and other public health care funds prior to expending P.L. 99-457 monies. Private insurers would have the primary financial responsibility because federal laws for Medicaid and Maternal and Child Health block grant programs stipulate that these programs are to be the payers of last resort, in cases where persons eligible for those programs also have private insurance. Private insurance should be seriously considered as a source of funds by administrators of early intervention programs. The types of early intervention services typically covered by private health insurance programs include speech therapy, occupational therapy, physical therapy, assistive devices, mobility aids, and communication devices in addition to many of the home health care services required by medically fragile children.

Because of the provision in Part H of P.L. 99-457 that allows parents to be charged a sliding fee where it is consistent with state law, the use of private health insurance may be slightly different for 0-2 year old children as opposed to 3-5 year old children. However, the basic process is the same. First, service providers determine what type of private health care insurance is carried by children and their families enrolled in early intervention programs. Second, whenever a service is provided to the child which is a part of that child's covered service, a bill is sent to the insurance company for reimbursement.

Although the process is straightforward, state education agencies have been reluctant to bill private insurers for services received by children with disabilities. In fact, only a handful of states (e.g., South Dakota, Illinois, Utah, Colorado, and

Connecticut) are systematically collecting revenues from private insurance coverage to help support such programs. There are a number of reasons that state administrators seem to be reluctant to access private health insurance. A part of this reluctance may be based on some of the following misinterpretations of federal policy.

- **Because states are required to provide "free" services to handicapped children, the use of private insurance coverage is inappropriate.** In fact, the regulations for Part B of EHA make it clear that private health insurance companies may not refuse to pay for health related services which are a part of a child's IEP simply because the state is responsible for providing a free and appropriate public education to all handicapped children (34 C.F.R. paragraph 300.301(b) (1982)).

- **Services for handicapped children must be provided at "no cost" to the family.** Although this language is used throughout EHA, policy letters issued by the federal government explain that as long as parents are not required to pay any deductibles for co-insurance payments, private insurance may be used to pay for services provided to handicapped children since premium payments are voluntary on the part of parents. Given the lack of clarity in Part H about the sliding feeds, it may even be permissible to require parents to pay the deductible or co-payment charges for some services.

- **Health related services required as a part of a child's IEP are considered educational in nature since they are delivered by an education agency and therefore are not reimbursable.** In fact, private health insurance plans typically do not reject claims because of the setting in which the service is provided as long as the service is deemed to be medically necessary and is delivered by the appropriate health care professional.

Even though there is nothing in the language of EHA that would preclude the use of private insurance to reimburse services associated with early intervention programs, a number of difficult implementation issues remain unresolved at the present time. For example:

- Can parents be required to utilize their health insurance coverage or must it be on a voluntary basis?

- If the use of private health insurance to cover early intervention services deducts from the policy's life-time benefit cap, is that considered to be a cost to a parent?

- Can the payment of co-payments, co-insurance, and deductibles be handled under a sliding fee mechanism for Part H children?

- Is it possible that the wider use of private health insurance to support early intervention services might result in increased premiums or cancelled policies for children with disabilities?

None of these issues are easily resolved and the questions concerning services to 3-5 year old children are more difficult than for 0-2 year old children because of the absence of any language concerning sliding fee mechanisms in Section 619. It is also clear that the collection of money from private health insurers requires substantial effort by a well organized system for collecting information from parents about the type of coverage they have, billing, and dealing with the questions of health insurers. Some states have been successful in contracting these responsibilities out to the private sector. Others have handled them as a part of a statewide mechanism.

In the few states that have developed systems for use by education agencies (e.g., Connecticut, Illinois and South Dakota), there is substantial reluctance on the part of administrators to become involved in such a billing and collection program. A part of this stems from the misinterpretations of federal policy, but a good deal of it appears to be a function of the reluctance on the part of educators to be viewed as a "health care agency." The complexity of billing procedures and the fears that there may be little gain for a large administrative effort, record keeping requirements and fear of possible litigation may also be disincentives.

Although the uncertainty associated with more frequent use of private health insurance is substantial, it is an issue which should be seriously considered by administrators of early intervention programs. Relying solely on limited public dollars may mean that fewer families are served and that essential but costly services are omitted from the child's IFSP or IEP. An excellent summary of some of the issues involved in developing a system to collect private health insurance revenues is provided by Fox and Neiswander (1988).

Sliding Fee Scales. As noted earlier, P.L. 99-457 states that "where federal or state law provides for a system of payments by families, including a schedule of sliding fees..." that such fees may be used as a part of the early intervention program. The potential of using sliding fees to generate revenues for early intervention programs is murky at best. Although the statute is unclear and the committee report and the regulations are silent on this issue, some have argued that it was not the intent of Congress to allow for the creation of new sliding fees, but only not to prohibit the use of sliding fees where they already exist.

For the time being, it is probably best for administrators not to depend on the use of sliding fee scales as a significant source of revenue to support early intervention programs. Indeed, the issue may be mute since most administrators will probably be reluctant to use sliding fees as a way to generate revenues because of a concern of excluding from service those who may need it most and of the difficulties associated with establishing sliding fee scales.

Print Resources

The following references and resources may be useful to administrators and service providers who are interested in a more in depth examination of current early intervention financing issues. The references include information about a variety of topics ranging from general background materials such as the nature of private and public health insurance for children to specific information on third-party billing systems, ending legislative and judicial actions, and "how-to" manuals. References that are particularly informative include #s 8, 10, 12, 17, 22, and 35.

1. Ballard, J., Ramirez, B., & Zantal-Wiener, K. (1987). **Public Law 94-142, Section 504, and Public Law 99-457: Understanding what they are and are not.**

   A question and answer format that addresses the "Amendments to the Education for All Handicapped Children Act, including revised definitions, regulations, and federal priorities." Available from: The Council for Exceptional Children, 1920 Association Drive, Reston, Virginia 22091.

2. Blackman, J. (1986). **Warning Signals: Basic criteria for tracking at-risk infants and toddlers.** National Center for Clinical Infant Programs, 733 15th St., Suite 912, Washington, D.C. 20005. (202) 347-0308.

   A publication resulting from the meeting of a 17-member interdisciplinary team convened by Project Zero to Three of the National Center for Clinical Infant Programs. Outlines basic criteria for identifying and including infants and toddlers in tracking systems designed to follow at-risk children.

3. Blue Cross and Blue Shield of Massachusetts. (1985). Position Paper by Blue Cross and Blue Shield of Massachusetts for the Joint Legislative Committee on Insurance in Opposition to H.1009 (AKA S.1711). An Act Relative to the Insurance Coverage of Early Intervention Services.

   While Blue Cross and Blue Shield are not opposed to providing legitimate health services, they consider early intervention services to be primarily educational and to be adequately funded by federal, state, and local public and private sources. This position paper offers insight into a potential response by the insurance industry to third-party billing for related services.

4. Colorado Department of Health. (1985). "Protocols for Insurance Billing Form."

   Because public health agencies may have difficulty claiming third-party reimbursements from private health insurance companies, the Colorado Department of Health developed this protocol to assist agencies in filling out health insurance forms. Included is an example insurance form and procedure codes.

5. The Colorado Developmental Disabilities Planning Council. (1986). **Special SSI and Medicaid Benefits: A guide for people who work or want to**

work. (A simplified guide explaining "work incentive" rules to SSI and Medicaid recipients.) **Pregnant and Wondering What to Do?** (1987). (A simplified guide to paying for prenatal care.)

These guides are examples of understandable directions for accessing the Medicaid system and may be useful to early intervention agencies interested in increasing financing from Medicaid through increased client eligibility. Available from: Colorado Developmental Disabilities Planning Council, 4126 South Knox Court, Denver, Colorado 80236. (303) 762-4448.

6. Committee on Child Health Financing. (1987). **Medicaid's EPSDT Program: A pediatrician's handbook for action**. American Academy of Pediatrics.

   A resource handbook to assist pediatricians in understanding and utilizing the EPSDT program. Includes EPSDT profiles by state. Available from: Judith Cohen or Nancy Matlin, Department of Child Health Care Finance and Organization. Phone Toll Free: 1-800-433-9016.

7. Commonwealth of Massachusetts. (1987). No. 1711. "An act relative to the insurance coverage of early intervention services."

   A bill proposed in the Massachusetts Senate to require that private health insurance cover early intervention services. This bill may provide a useful model for states interested in pursuing similar legislation.

8. Cox, J.O., & Black, T. (1982). **Analyzing costs of services**. Technical Assistance Development System (TADS).

   Geared toward administrators of early intervention programs, this book provides "how-to" information on analyzing program costs, including gathering and analyzing cost data and use of results. Available from: Publications, National Early Childhood Technical Assistance System (NECTAS), CB #8040, 500 NCNB Plaza, Chapel Hill, North Carolina 27599-8040.

9. Elder, J.O. (1987). **Blueprint for implementation of Part H, P.L. 99-457.**

   A process guide to implementing the 14 minimum components of Part H for state and local administrators of infant and toddler early intervention programs. Available from: J.O. Elder Associates, 9806 Parkfield Drive, Austin, Texas 78758. (512) 835-7611

10. Fox, H.B., & Neiswander, L. (1988). **Private health insurance financing for early intervention services.**

    Explores the potential use of private health insurance to help finance early intervention services to infants and toddlers under P.L. 99-457, Part H. Available from: Fox Health Policy Consultants, 1140 Connecticut Avenue, N.W., Suite 1205, Washington, D.C. 20036. (202) 223-1500

11. Fox, H.B., Neiswander, L., & Yoshpe, R. (1987). **Briefing memoranda for meeting on the feasibility of high-risk pools to provide health insurance protection for children with special health care needs.**

    An overview of the chronically ill child population and its access to health insurance, the high-risk pool concept, its utility for children, the expense to states, and other public policy options. Available from: Fox Health Policy Consultants, 1140 Connecticut Avenue, N.W., Suite 1205, Washington, D.C. 20036. (202) 223-1500

12. Fox, H.B., & Yoshpe, R. (1987). **Medicaid financing for early intervention services.**

Summarizes the potential for utilizing the Medicaid EPSDT (Early and Periodic Screening, Diagnosis, and Treatment) program to help finance early intervention services to handicapped infants and toddlers under P.L. 99-457, Part H. Available from: Fox Health Policy Consultants, 1140 Connecticut Avenue, N.W., Suite 1205, Washington, D.C. 20006. (202) 223-1500

13. Governor's Task Force on Catastrophic Medical Expenses and Utah Department of Health, Bureau of Planning and Policy Analysis. (1988, March). Report of the Governor's Task Force on Catastrophic Medical Expenses.
    An analysis of the potential and recommendations for developing a high-risk insurance pool in the State of Utah for individuals who have difficulty obtaining adequate health insurance due to pre-existing health conditions. Available from: Utah Department of Health, Bureau of Planning and Policy Analysis, 288 North 1460 West, Salt Lake City, Utah 84116.

14. House Fiscal Agency, State of Michigan. (1986-87). "The 1986-87 compiled school aid act."
    A result of efforts by Michigan to provide legislative authority to education agencies for third-party billing. The compiled School Aid Act contains language requiring parents to use their medical insurance to pay for related services. Available from: House Fiscal Agency (517) 373-8080.

15. Interagency Committee for Children in the State of Maryland. (1987). "Progress Report: Interagency plan for children with special needs."
    A progress report on the efforts of the State of Maryland to provide more coordinated services to special needs children, including specific tasks and time tables. Available from: Maryland State Department of Education, Division of Special Education and Support Services, 200 West Baltimore Street, Baltimore, MD 21201-2595.

16. Margolis, L.H., & Meisels, S.J. (1987). Barriers to the effectiveness of EPSDT for children with moderate and severe developmental disabilities. **American Journal of Orthopsychiatry**, 57(3), 424-430.
    The authors identify structural features of the EPSDT program, lack of public awareness, health personnel training and attitudes, and lack of access to follow-up care as barriers.

17. Massachusetts Department of Public Health, Division of Family Health Services. (1986). "Early intervention unit rate billing instructions."
    Instructions for billing Medicaid for reimbursable early intervention services which were developed as a part of the unit billing system for Massachusetts' comprehensive and coordinated early intervention program. Included are definitions and specifications of billable services, approved program rates, billable staff members, special billing policies, contractual guideline, and documentation guidelines.

18. McManus Health Policy, Inc. (1987). **Guide to state financing data sources with emphasis on children with special health care needs.**
    The second of a series of three publications, this is a guide to assist in the collection and use of data from State Programs for Children with Special Health Care Needs (CSHCN) and State Medicaid programs. The other publications in the series include: **Guide to National Data on Maternal and Child Health** and **Consumer's Guide to Financing Information for Families of Children with Special Health Care Needs**. Available from:

McManus Health Policy, Inc., 4801 Massachusetts Avenue, N.W., Suite 400, Washington, D.C. 20016. (202) 895-1580

19. Meisels, S.J. (1984). Prediction, prevention, and developmental screening in the EPSDT program. In H.W. Stevenson & A.E. Siegel (Eds.), **Child Development Research and Social Policy.**
    A critique of the history and assumptions upon which the EPSDT program is based. This chapter provides useful insight into the reasons that the EPSDT program has not lived up to its promise as effective federal legislation to improve child health.

20. Meisels, S.J., & Margolis, L.H. (In press). "Is EPSDT effective with developmentally disabled children?"
    This study concludes that EPSDT is not effective with this sample of DD children. Policy recommendations include modification of the EPSDT screening components, increase training for EPSDT staff in working with handicapped children, and improved interagency cooperation. Available from: Samuel J. Meisels, Ed.D., Center for Human Growth and Development, The University of Michigan, 300 North Ingalls, Ann Arbor, Michigan 48109.

21. National Association of State Directors of Special Education. (1986). "Changes in services to children 3-5 years old: P.L. 99-457: Education of the Handicapped Act Amendments of 1986, Title II--Handicapped Children aged 3 to 5." **Liason Bulletion, ?**
    Presents previous and P.L. 99-457 statutory language with corresponding language from the House of Representatives report accompanying the act regarding preschool grants, application, entitlements and allocations, payments, and authorization and appropriations. Available from: National Association of State Directors of Special Education, 2021 K Street, N.W., Suite 315, Washington, D.C. 20006. (202) 296-1800, Specialnet User Name: NASDSE.

22. National Association of State Directors of Special Education. (1987, October). Financing medically related services for children with handicaps: The potential role of Medicaid. **Liaison Bulletin,** 12(12).
    An excellent analysis of the issues and chronological history of legislative and judicial policy regarding financial responsibility for related services.

23. National Association of State Directors of Special Education. (1986). "Sharing of costs of free appropriate public education: An analysis of P.L. 99-457 amendments."
    Presents previous and P.L. 99-457 statutory language with corresponding sections of the GAO report, "Special Education--Financing Health and Educational Services for Handicapped Children" regarding supplement, not supplant, and interagency coordination. Available from: National Association of State Directors of Special Education, 2021 K Street, N.W., Suite 315, Washington, D.C. 20006. (202) 296-1800, Specialnet User Name: NASDSE.

24. National Center for Clinical Infant Programs. (19___). "Keeping track: Tracking systems for high-risk infants and young children."
    Findings of a 1984 meeting on systems for identifying and tracking high-risk infants. Includes examples of tracking systems from several states. Available from: National Center for Clinical Infant Programs, 733 Fifteenth Street, N.W., Suite 912, Washington, D.C. 20005. (202) 347-0308

25. O'Shaughnessy, C., & Price, R. (1985). "Medicaid 2176 waivers for home and community-based care 85-817 EPW."
Information is presented about the types of waivers granted, case examples, and issues related to community waivers are raised. This report summarizes background, legislative history, and regulations for the community-based waiver program which allows states to provide this community-based services rather than institutionalization to Medicaid eligible individuals. Available from: Congressional Research Service, The Library of Congress, Washington, D.C. 20540.

26. Roelofs, M. (undated). Trans Allied-Medical-Educational Services, Inc. (TAMES).
TAMES is a private, for-profit, 3rd party billing system designed to assist education agencies in billing Medicaid and private health insurance carriers for the cost of related services to handicapped children. Publications Include: A How-To Manual for Establishing Agreements with State's Department of Medicaid, Health Insurance Carriers and Health Maintenance Organizations. Proposed Federal/State Initiatives for Children's Access to Health Care Services--TAMES suggests Federal mandates to: 1) establish a basic out-patient pediatric health-care plan for children; 2) establish public agencies eligibility for third-party reimbursement; and 3) establish single health care language terminology.

27. Rosenbaum, S. (1986). "Children and Private Health Insurance."
An examination of major trends in private health insurance for children, including eligibility, benefits, cost sharing, methods of administration, and feasibility for improving coverage. Available form: Sara Rosenbaum, Children's Defense Fund, 122 C Street, N.W., 4th Floor, Washington, D.C. 20001. (202) 628-8787

28. State of Utah. (1986). **Medicaid: Your guide to medical assistance.**
An information guide for Medicaid applicants in question-answer format. Another example of understandable directions for accessing the Medicaid System. Available from: State of Utah, Department of Health, Division of Health Care Financing, Medicaid Information, P.O. Box 16700, Salt Lake City, Utah 84116-0700.

29. Trippler, A.K. (1987). **Comprehensive health insurance for high risk individuals: A state-by-state analysis** (2nd. edition).
A state-by-state report of legislative activity to create high-risk insurance pools for individuals who have difficulty obtaining adequate and reasonable health insurance due to pre-existing health conditions. Includes a summary of each state's high-risk pool history and current status, examples of legislation, and operational data. Available from: Communicating for Agriculture, CA Support Services Office, 2001 Killebrew Drive, Suite 169, Minneapolis, MN 55420. (612) 854-9005

30. U.S. Court of Appeals for the First Circuit. (1987, March). No. 86-1109: Commonwealth of Massachusetts v. Secretary of Health and Human Services. No. 86-1118: Commonwealth of Massachusetts, Department of Public Welfare v. Secretary of Health and Human Services.
Pending court decision. At issue is whether related services are reimbursable by Medicaid in ICF/MRs. These court cases may potentially effect decisions about Medicaid's responsibility in paying for related services provided by education agencies to Medicaid-eligible children.

31. United States Department of Education. (1987). Proposed rules 34 CFR Part 301, Preschool Grants for Handicapped Children Program. Federal Register (52)222, 44346-9.

United States Department of Education (1987). 34 CFR Part 303. Early Intervention Program for Infants and Toddlers with Handicaps; Notice of Proposed Rulemaking. Federal Register (52)222, 44352-63.

The proposed rules for these programs, if adopted, will expand understanding and provide guidelines for implementing P.L. 99-457.

32. United States Department of Education. (1988).

A report of the joint study conducted by the Secretary of Education and the Secretary of Health and Human Services will be available in May, 1988. It will examine current federal funding sources and early intervention programs available to handicapped infants and toddlers. It will also address federal level interagency coordination of those programs and procedures to ensure that current funding under those programs is not withdrawn. Direct inquires to: The Office of the Secretary of Education.

33. United States Department of Health and Human Services. (1986). Medicaid Services State-by-State. Health Care Financing Administration, Office of Intergovernmental Affairs.

A table comparing Medicaid services offered by state which includes rates of federal financial participation. This table is updated yearly and provides a visual overview of the required and optional Medicaid services in each state.

34. United States Department of Health, Education, and Welfare. (1976). **Recipes for Success: Head Start and EPSDT**. DHEW Publication No. (OHD) 77-31097.

An older manual designed to assist Head Start personnel in utilizing EPSDT services for young children. **Recipes for Success** provides background information about the connection between Head Start and EPSDT. Also included are recommendations for collaboration between Head Start and state and local health and welfare agencies, outreach to parents, transportation, reimbursement, and record keeping. A useful compilation of practical Head Start experience. Available from: Project Head Start, Administration for Children, Youth, and Families, Office of Human Development Services, Department of Health and Human Services, Washington, D.C. 20201.

35. United States General Accounting Office. (1986, July). Briefing report to the Chairman, Subcommittee on Selection Education, Committee on Education and Labor, House of Representatives: Special Education: Financing Health and Educational Services for Handicapped Children.

This document explores interagency agreements as a means of utilizing resources of various state agencies in financing services to handicapped children. The experience of Connecticut in using Medicaid to help finance school-based health services, and of Maryland in utilizing health and social services funding to pay for residential placement is documented. Available from: U.S. General Accounting Office, P.O. Box 6015, Gaithersburg, MD 20877. (202) 275-6241

36. United States General Accounting Office. (1987, May). Briefing report to the Honorable Daniel Patrick Moynihan, United States Senate. Medicaid: Interstate variations in benefits and expenditures.

A report comparing eligibility criteria for Medicaid, the scope of services

offered, and reimbursement to providers across states. The increase in the Medicaid eligible population, inflation, and the shift from acute to chronic care are identified as determinants of increased Medicaid spending. Broad federal guidelines, the availability of state financial resources, and socio-political differences between states account for the inequities in benefits. A good summary of how state's political and ideological attitudes affect the availability of Medicaid resources. Available from: U.S. General Accounting Office, P.O. Box 6015, Gaithersburg, MD 20877. (202) 275-6241

37. United States General Accounting Office. (1987, April). Medicaid: Addressing the needs of mentally retarded nursing home residents. Report to the Secretary of Health and Human Services.

    An examination of Medicaid supported nursing homes in Connecticut, Rhode Island, and Massachusetts to determine whether mentally retarded residents receive adequate services to help them function independently. Findings indicate that services are inadequate due to poor screening of residents, inadequate care plans, and inadequate inspections of services. These findings may be relevant to Medicaid's position which does not allow Medicaid reimbursement of related services identified in the IHPs of ICF/MR residents. Available from: U.S. General Accounting Office, P.O. Box 6015, Gaithersburg, MD 20877. (202) 275-6241

38. United States General Accounting Office. (1985, February). Report to the Congress of the United States: Improved efforts needed to relieve Medicaid from paying for services covered by private insurance.

    A report describing how state Medicaid practices for identifying and collecting private insurance could be improved. Medicaid's position as the payor of last resort is emphasized. Available from: U.S. General Accounting Office, P.O. Box 6015, Gaithersburg, MD 20877. (202) 275-6241

39. United States House of Representatives. HR 3454 (1987). 100th Congress, 1st Session--Medicaid home and community quality services act of 1987.

    Proposed amendment to Title XIX of the Social Security Act which would provide Medicaid funds for home and community-based services to persons with severely disabilities. This is identical to the bill introduced in the Senate as S.1673.

40. United States House of Representatives 99th Congress, 2nd Session. Report 99-860 Report Accompanying the Education of the Handicapped Act Amendments of 1986.

    The text expands on and explains the legislative intent of each section of P.L. 99-457.

41. U.S. Congress, Office of Technology. (1987, May). Technology-dependent children: Hospital v. home care--A technical memorandum, OTA-TM-H-38 (Washington, D.C.: Government Printing Office).

    Report defines "technology-dependent children," estimates the population, explores relative cost and effectiveness of hospital vs. home care, and explores sources of financing home care. Available from: Superintendent of Documents, U.S. Government Printing Office, Washington, D.C. 20402-9325 ($4.95).

42. Weiner, R., & Koppelman, J. (1987). **From birth to 5: Serving the youngest handicapped children**. Virginia: Capitol Publications, Inc.

A recent book exploring concerns and issues related to the implementation of P.L. 99-457 based on interviews with administrators, service providers, and consultants to early intervention programs.

43. White, K.R. (1987, December). Minutes of the Consortium on More Effective Utilization of Medicaid and Third-Party Payments to Support Early Intervention Programs Under P.L. 99-457.

Minutes from a meeting of state-level health and education administrators from Colorado, New Jersey, Massachusetts, and Utah exploring current and potential third-party billing practices. Included are summaries of current practices from each state. Available from: The Early Intervention Research Institute, Developmental Center for Handicapped Persons, Utah State University, Logan, Utah 84322-6580. (801) 750-1172

Potential Sources Of Technical Assistance

The following persons or agencies are currently working with early intervention financing issues. Many of these would be in a position to provide technical assistance to state agencies responsible for the development of early intervention programs for handicapped children.

American Academy of Pediatrics
Department of Child Health Care and Financing
141 Northwest Point Blvd.
P.O. Box 927
Elk Grove, IL 60009-0927
Judith Cohen or Nancy Matlin (1-800-433-9016)

Children's Defense Fund
122 C Street, N.W.
4th Floor
Washington, D.C. 20001
(202) 628-8787

Council for Exceptional Children
1920 Association Drive
Reston, VA 22099
(703) 620-3660

Early Intervention Research Institute
Utah State University
Logan, UT 84322-6580
(801) 750-1172

Harriette Fox, Ph.D.
Fox Health Policy Consultants
1140 Connecticut Ave., N.W.
Suite 1205
Washington, D.C. 20036
(202) 223-1500
Don Kates

Georgetown University
3615 Wisconsin Avenue, N.W.
Washington, D.C. 20016
(202) 364-4166
[Associated with the National Early Childhood Technical Assistance System]

McManus Health Policy, Inc.
4801 Massachusetts Ave., N.W.
Suite 400
Washington, D.C. 20016
(202) 895-1580

National Association of State Directors of Special Education
2021 K Street, N.W.
Suite 315
Washington, D.C. 20006
(202) 296-1800

National Center for Clinical Infant Programs
733 Fifteenth Street, N.W.
Suite 912
Washington, D.C.
(202) 347-0308

National Early Childhood Technical Assistance System (NECTAS)
500 NCNB Plaza
CB #8040, University of North Carolina
Chapel Hill, NC 27599-8040
(919) 962-2001

Trans Allied-Medical-Educational Services, Inc. (TAMES)
Marv Roelofs, Executive Director
800 Governors Highway
P.O. Box 460
Flossmor, IL 60422
(312) 957-7004

SUMMARY

There are many important decisions to be made around P.L. 99-457 which will affect the quality of the resources that can be made available to children with special needs and their families. These involve issues of who can be served, the types of programs available and their relative effectiveness, the training of personnel, the coordination of resources and the nature of the system that carries out all the functions called for in the law. While some may picture financing as the brick wall that is hit on the way to a quality program, unlimited financing by itself will not lead to quality resources. In the next chapter, we will explore issues related to personnel planning and development, major factors in determining the quality of services.

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Fox, H.B. & Neiswander, L. (1988). **Private health insurance financing for early intervention services.** Washington, D.C.: Fox Health Policy Consultants.

Fox & Yoshpe. (1987). **Medicaid financing for early intervention services.** Washington, D.C.: Fox Health Policy Consultants.

Gilkerson, L., Hilliard, A.G. III, Schrag, E., & Shonkoff, J.P. (1986). **Report accompanying the Education of the Handicapped Act Amendments of 1986.** (House Report #99-860). Washington, D.C.: National Center for Clinical Infant Programs.

Odom, S.L., & Fewell, R.R. (1983). Program evaluation in early childhood special education: A meta evaluation. **Educational Evaluation and Policy Analysis,** 5, 445-460.

Weiner & Koppelman. (1987). **From birth to 5: Serving the youngest handicapped children.** Virginia: Capitol Publications, Inc.

CHAPTER 8

What personnel will be needed to provide these resources and services and how will they be prepared?

Early intervention--as a service, a resource--takes place in the interaction between families and direct care therapists, social workers, physicians, nurses, psychologists, and early childhood educators and others. What kind of people can carry out this service in the spirit of the new law? How does one learn both disciplinary skills and how to collaborate effectively with families? While we know that disciplinary expertise is important, families will rarely mention "expertise" first when called on to describe the professionals who have been most helpful to them.

"I think the professional who affects me the most is one that has openness," says one mother. "She may not like a particular theory or treatment or intervention, but she's willing to watch the videotape, to read the book, to listen to the presentation."

"Our physical therapist is the one that I like the best," says a father. "She's been in our home and seems to know where we're coming from. And she doesn't do just therapy, she doesn't just do stuff related to Deb's disabilities. She helps with a lot of overall parenting things, normal helpful suggestions."

"It would be nice if they were just human beings first, and professionals second," summarizes another parent.

While parents want experts in particular areas, what they respond to most is the quality of interpersonal support during a particularly difficult time in the life of their family. Some might argue that people cannot be trained to provide these qualitative elements, that you need good people to start with. Others will say that since we do not know definitely what kinds of services are most effective with families of children with special needs, how can we guess what professionals can best carry out those programs?

But the law asserts that we know enough to get started on this process, and that personnel standards and a plan for personnel development are critical to the system. The report accompanying P.L. 99-457 states:

> "The system must include training in public and private service providers, primary referral sources, and person who will provide services after receiving

> such training. Services and training may be provided directly by the State or through a grant, contract or other arrangement with other entities" (U.S. House of Representatives, 1986).

To support this statement, P.L. 99-457 authorizes funds for personnel preparation. The law states that grants may be made to institutions of higher education and appropriate nonprofit agencies to assist them in training personnel for careers in disciplines that provide early intervention services.

In this chapter the issues and options that are critical to carrying out a personnel plan will be reviewed, including the issue of personnel shortages, defining related services, qualifications related to age of the child, specific areas of expertise for individuals working with children in the 0-2 age group, standards and certification issues, curriculum issues, maintenance of personnel and concerns of evaluation. Issues related to personnel serving children from birth through age 5 are included, but an emphasis will be on the 0-2 group covered under Part H.

Shortages

One immediate impact of P.L. 99-457 is that the numbers of children eligible to receive services will increase. This will require an increase in personnel who provide services to these children. This need for personnel comes at a bad time, as there already exists a chronic and critical shortage of trained personnel in early childhood special education (McLaughlin, Smith-Davis and Burke, 1986) and related early intervention personnel (Meisels, Harbin, Modigliani and Olsen, in press). In a 1986 survey of all states, nearly 90% of respondents reported they lacked personnel to adequately serve children with disabilities from birth through age 2, while 80% said they could not provide full services to children ages 3 to 5 (Weiner and Koppelman, 1986).

This shortage is affecting all areas of education for children who are handicapped. This concern was expressed in the House Report accompanying P.L. 99-457:

> "The Committee is greatly concerned that shortages of qualified personnel in the provision of special education and related services to handicapped children are reaching crisis proportions. The data reported in testimony before the subcommittee indicates that approximately one-fourth of the personnel in special education do not now meet State certification standards. In a number of

school districts, vacancies are going unfilled, class size and caseloads are increasing, the number of colleges and universities offering training programs is declining, and almost all States report that they are unable to fill these personnel needs from training programs within their borders. Five- and ten-year projections suggest an even worsening situation (U.S. House of Representatives, 1986).

This concern extends to providers of related services as well as special educators. A recent survey of all states and the District of Columbia (Meisels et al., in press) obtained information on the need for personnel in the related services of physical, occupational, and speech therapy. For the birth through 2-year-old group, 96.2% of the states reported a shortage. A 98.1% shortage was reported for the 3 to 6 age group.

These statistics, at first, seem forbidding, but there is a positive side. The opportunity is present for states and training facilities to develop a coordinated program of service and training. At present, state early intervention programs and the training programs designed to prepare personnel to serve in them are not well coordinated (Bricker and Slentz, in press). These activities can become, and need to become, more systematic as personnel needs increase and states solidify intervention plans. Until these coordinated activities are developed, a transition stage will be in effect. During this time, states will need to determine patterns of service delivery and set standards for personnel. Universities will need to outline curricula, and inservice training for personnel already in the field will need to be developed. The end result can be a system that works for all parties involved--teachers, teacher trainers, state administrators, and above all, the children and families. States that have been providing early intervention services since the 1970s, such as Nebraska and Iowa, affirm that the process does work.

Related Services

A question that may be raised is: "What personnel constitute related services?" This question is not directly answered in P.L. 99-457, but many disciplines can and should be involved in early intervention. These disciplines include speech-language pathology, audiology, physical and occupational therapy, health professions, social work and administration. Although P.L. 99-457 is referred to as an education act, early intervention for the infant group may be based in a number of settings.

Those services which have been considered related services for preschool-aged and school-aged children will frequently be primary services for the birth through age 2 group.

What constitutes a related service will depend on the age of the child, as the regulations for children from birth through age 2, and age 3 through 5 differ. Related services for the infant group encompasses a wider array of disciplines, because the definition of "handicapped," at this level, is very broad. A handicapped infant is defined as a child having a developmental delay as measured by appropriate diagnostic instruments and procedures, and as a child who has a diagnosed physical or mental condition which has a high probability of resulting in a developmental delay. Unlike the preschool group, the delay does have to be one that interferes with the child's educational program. The personnel for an infant might be a nutritionist and a social worker, both of whom function as primary service providers.

For children in the preschool group, the personnel that will provide services will be the same as those that currently provide services under P.L. 94-142, with some exceptions. States may establish different criteria for the preschool group to receive services than those criteria established for school-age services. The manner in which eligibility for services is defined by a State will influence service needs and personnel to provide these services. Although, these preschool-group personnel needs should not differ significantly from personnel needs that currently exist.

Differences in Competencies Needed for Early Intervention

Personnel for the infant group (children from birth through age 2) will differ from those needed to serve the preschool group (children from 3 to 5 years of age), and these will both differ from personnel in the school-age group. Graduates of special education programs are usually trained to teach in kindergarten through high school in a specialty area. These teachers are not prepared to assume the responsibilities of the young children with disabilities (Karnes, 1975). These different responsibilities apply not only to educators, but also to the other disciplines that work with young disabled children.

Educators of children without disabilities will attest to the fact that different skills are needed for different age groupings. In many states, education is divided into early childhood, elementary, middle, and secondary certification areas. That special education training institutions are able to prepare teachers to work with students from kindergarten through high school is an accomplishment in itself. To expect this training to extend from birth to high school would place extraordinary demands on teacher trainers and on the students being prepared to teach. The end result would be to dilute the training experience, which would affect services provided to the handicapped child.

What are the primary areas of difference between professionals who work with young handicapped children and those who work with school-age handicapped children? Recently, an article described the competencies needed by school psychologists to work in early intervention (Bagnato, et al., 1987). These competencies can be adapted and additions made to describe the special skills needed by all who work with young children with disabilities. They include an emphasis on the family, case management, interdisciplinary skills, developmental principles, a functional orientation, and the ability to work in diverse settings.

Family Emphasis. Families are a new emphasis in the Part H program, and the Individual Family Service Plan (IFSP) is the legal service document. In order to generate good quality IFSPs for the full range of eligible infants/toddlers and their families, the personnel responsible for developing IFSPs must have abilities in a number of areas. Good clinicians have always had the ability to put good plans together. New training efforts for the IFSP will involve trying to describe that process for people who do not have these skills.

There are currently very few models for family service planning in the field of early intervention. Thus, developing IFSPs will be a new undertaking for many professionals working with children under three years of age. Campbell et al. (1987) suggested that the areas of multidisciplinary evaluation of family needs, including family members as part of the multidisciplinary team and the appointment of an appropriate case manager, will be the most critical new skill for personnel involved in generating IFSPs.

Case Management. The case management component of the IFSP will involve new skills for many early childhood personnel. For example, a child born with an extremely low birth weight may be eligible for services. At birth, there is a need for the child to be identified as needing services and then for the child to be monitored while in the hospital. This would involve contacts with doctors and nursing staff. At discharge from the hospital, family-focused intervention in the form of nutritional counseling and providing information on known risks may be necessary; services that could be delivered by nurses, social workers, or an early interventionist. At 6 months, the child may require occupational or physical therapy for motor problems. At 24 months of age, the child's motor skills may be developmentally appropriate, but language and cognitive problems may have developed requiring a speech pathologist and an early interventionist. When the child reaches 36 months, he may be eligible for preschool services; requiring assistance with transitioning between programs. At 60 months, the child may need to move into a school-age program, again changing the professionals with whom the child and parent interact.

Case management requires personnel who can work across disciplines and settings. When children come to transition points in their educational career--infant to preschool services and preschool to school-age services---these transitions will need to be carefully planned. Case management activities, along with records, need to transfer with the child. In some situations, services may have been provided by different agencies. In these cases, interagency cooperation will be necessary. The case manager must be able to access all child relevant records, regardless of agency. This will help avoid duplication of services and help eliminate the needs for parents to move their child from setting to setting.

Interdisciplinary Skills. Working with young handicapped children requires an interdisciplinary approach. The skills a delayed young child needs to learn cannot easily be separated into distinct areas. Cognitive skills, motor skills, language skills are intertwined at this level, making it difficult to work on any one skill in isolation. For example, if a child cannot express himself, it makes many forms of peer interaction difficult and affects self-help skills such as indicating a need to use the bathroom. Although all disciplines are regarded as unique, their overlap at these early age levels suggest that services will be more effective if an interdisciplinary team is used and a transdisciplinary approach to services is taken.

Parents must be interdisciplinary people and it is clearly the intent of the law that parents be central players on the interdisciplinary team. Children are not segmented into different skills and parents want professionals to behave in an interdisciplinary manner as well. "I like to be around professionals when you really can't pinpoint exactly what their profession is," says one parent. "They are so comfortable with the concept of early intervention and early childhood and its good to see a home intervention teacher and an occupational therapist sit on the floor together and interact with my child. And talk to each other."

Another parent agrees. "I don't like to see people securing their own job by not sharing their skills with parents and the other people they work with. It's as if they're saying, If I teach her how to do this evaluation then they won't need me anymore."

Developmental Principles. A strong foundation in normal and atypical development is required to work with young delayed children. What is appropriate at different age levels is not as clear cut as with older children. A strong developmental foundation provides a base from which to develop appropriate developmental objectives, teaching/learning strategies, and programs for maintenance and generalization of skills. In addition, the least restrictive environment aspects of early intervention, as emphasized in P.L. 99-457, will result in situations where services will need to be provided to delayed and non-delayed children in the same setting. A normal developmental foundation will help provide appropriate skills to deal with mainstream service models.

Functional Orientation. The needs of early intervention require that service personnel be able to work with children from birth through 5 years of age who are not categorized by nature of their delay. Early interventionists must be trained to provide services to behaviorally disordered preschoolers, toddlers with cerebral palsy, deaf/blind infants, and those with other handicapping conditions. This requires that personnel approach individual children from a functional perspective. Selecting intervention goals from a single curriculum is not appropriate. Intervention goals must reflect the needs of a particular handicapping condition while enabling the child to increase interactions with her environments.

Diverse Settings. In the House Report accompanying P.L. 99-457 (U.S. House of Representatives, 1986), it is made clear that there exists a variety of effective educational models for serving young handicapped children, and it is implied that these alternative delivery systems should be available service options. Examples of such options include Head Start centers, community day care centers, hospital-based programs, and school-based programs and home-based programs. Personnel serving young handicapped children need to learn the advantages and disadvantages to serving children in these varied settings, and also how to best provide services in each.

Infants and Preschoolers--Together or Separate

The provision of intervention services to infants may be a relatively new venture for many states. It is the consensus of many professionals that the services provided to infants sufficiently different from those provided to preschoolers to require special preparation (e.g., Bailey, et al., 1986; Bricker and Slentz, in press; Farel, Bailey and O'Donnell, 1987). In a recent survey of early intervention personnel preparation programs, 89% of the respondents agreed that the training of personnel for the infant group should differ from the training provided to those in the preschool group (Bricker and Slentz, in press).

This consensus is reflected by early interventionists providing services. A study was conducted in Illinois to delineate the similarities and differences of the role of those providing services to infants from those providing services to preschoolers (McCollum, 1987). Illinois has had mandated preschool services since the mid-1970's and has concurrently offered services to infants, although these infant services are not mandated. Infant services consist of center- or home-based visits delivered by an infant interventionist for 1 to 2 hours, once or twice per week. Preschool services are delivered in half-day classroom programs that occur 5 days per week. These service delivery patterns are commonly occurring ones.

McCollum (1987) conducted a survey to determine the percentage of time infant interventionists and preschool teachers spent in various occupational roles. Differences were found in the percentage of time the providers spent in a variety of activities. Infant interventionists reported spending more time in roles related to supporting families and working with other professionals. Preschool teachers reported more time in teaching groups of children, organizing the learning environment, and developing teaching activities; a more traditional role. It should be noted that all providers spent time in all role areas listed, only the amount of time varied. These service providers also completed a survey regarding the ideal emphasis of preservice training, and their responses reflected their current roles.

This study clearly points out the differences in the role played by service providers of the two groups, but it also points out the similarities. It is clear that training institutions who prepare interventionists for working with young delayed children will need to emphasize some different skills for infants or preschoolers, but that a common core of skills is also necessary. These concerns regarding the skills needed by those that work with infants and those working with preschoolers must be considered when training and when personnel standards are established. It is clear that the role of the early interventionist, the skills needed for this role, and the setting in which this role will be played is in a process of continuing development (Bailey et al., 1986).

Standards and Certification Issues

Although P.L. 99-457 sets guidelines for the services that are required for children, the law leaves the determination of standards for personnel, as well as the policies and procedures for establishing and maintaining the standards, to each state.

The law does specify that the standards established by the state should be based on the highest requirements in the state that are applicable to a specific profession or discipline. If the standards adopted by the state are not the highest required by a profession or disciplines, the state must outline a set of requirements that insures personnel will be able to appropriately serve children's needs in that discipline. Some of the decisions that need to be made involve deciding whether to set lower standards in order to meet the new demands, or set the highest standards and allow waivers to allow the gradual adherence to those standards.

The issue of certification is a thorny one in the area of early intervention. Advocates of early intervention favor certification; some even favor separate certification for infants and preschoolers. School administrators are generally against specific certification, as it limits their flexibility in assigning personnel. Regardless of whether certification is required, clearly stated standards for people providing early intervention services are essential for the delivery of high-quality services.

All states and the District of Columbia have certification policies for school-age special education teachers (Abeson and Fleury, 1972). The specific question is whether personnel working in the area of early intervention should receive specialized certification. Both P.L. 99-457 and the House Report accompanying P.L. 99-457 say personnel should be "appropriately and adequately prepared and trained" (U.S. House of Representatives, 1986). The certification issues that arise can be divided into three general areas: the primary early interventionist, other service providers, and professionals and paraprofessionals currently working in the field of early intervention who are not certified.

The Primary Early Interventionist. There are currently 16 States that require early interventionists at the preschool level to hold preschool special education teaching certificates or add early childhood requirements to general special education certificates (McLaughlin et al., 1986). When standards for early intervention certification are established, it will be important to determine standards based on skills and competencies, rather than basing standards solely on training in some specific university departments. Appropriately trained early intervention personnel could, potentially, be prepared in many different academic departments (e.g., special education, nursing, early childhood, physical therapy, psychology, etc).

There are four main arguments in favor of certification:

1. Different skills are needed by those in early intervention than those that work with school-age children. Experts in the field concur on this point. The Council for Exceptional Children (CEC), the primary organization representing special educators, and the Division for Early Childhood (DEC) of CEC stress the need for certification, and CEC is determining standards

for such certification (Weiner and Koppelman, 1986). These certification standards should be reviewed by all who train early intervention personnel to insure that all skills/competencies needed are included.

2. Certification will help insure that quality services are provided by competent personnel. Research has indicated that structured programs are associated with more effective child outcomes (Casto and Mastropieri, 1986; Casto and White, 1985), qualified personnel can help increase structure.

3. Certified personnel have been found to be significantly more effective for increasing positive child outcomes than those who were not certified (Tingey-Michaelis, 1985). It should be noted that what was meant by certification in this research was not always clear. This is a problem that has occurred in other instances (cf., Smith and Powers, 1987).

4. There is currently a shortage of institutions to prepare early intervention personnel. Unless certification is mandated by states, institutions will be reluctant to begin new early intervention programs. Certification guarantees institutions that a population of people in need of training will be available.

The question of separate certification for early interventionists that work with infants and those that work with preschoolers is difficult to answer. It is clear that an argument can be made in favor of separate certification based on needed skills (cf., Bricker and Slentz, in press). On the other hand, there currently exists a severe shortage of personnel to provide early intervention services; there may not be a sufficient mass of people for universities to offer separate programs. Issues of practicality, in the face of a personnel shortage, will make separate certification difficult. Another issue, related to increasing available personnel, is the willingness of students to commit to a narrowly focused specialization (with its potentially limiting employment options) versus broader training in a general area.

This issue of separate early intervention certification will also depend, to some extent, on the type and nature of services that a state adopts As noted earlier, states are not mandated by P.L. 99-457 to provide services for at-risk infants. If a state opts to provide services to a wide range of delayed and at-risk infants, including medically at-risk infants, with a large array of service options, then infant certification or endorsement may be beneficial. States that offer to provide a more restrictive infant service option may be more flexible in their certification options.

Other Service Providers. It is clear that professionals other than early interventionists will be required to work with young delayed children. Most professions have some certification or licensure policies. These policies exist for speech pathologists, physical therapists, occupational therapists, psychologists, nurses, social workers, and others. The certification/licensure policies for each profession are different and many do not focus on skills seen as essential to early intervention, such as working on interdisciplinary teams and collaborating with parents. It would be unreasonable for states to expect these professionals to obtain early intervention certification. Such a requirement may drive these professionals away from early intervention. It is also not reasonable to expect each profession to adopt early intervention endorsement standards. In most professions, those involved in early intervention would constitute a small percentage of those who receive certification/licensure.

Training institutions need to be kept aware of the skills their graduates need to work in early intervention, even though only a small percentage of their trainees work primarily in that area. It would be advantageous if training institutions could provide experiences relevant to a variety of disciplines that work in early intervention. For example, a program that provides training to certify early interventionists may provide some courses, such as those teaching family support skills and those providing an interdisciplinary orientation, to other disciplines. These training institutions could then offer an endorsement stating that such training has been received. San Francisco State University is an example of a training institution that has implemented such a program (Hanson, Hanline and Petersen, 1987). States could then look for relevant courses or practica when hiring in these different disciplines. People in these other needed disciplines could also receive early intervention skills training at the inservice level through structured, regularly offered inservice activities. Coordination between states and training institutions could result in an efficient and practical system to meet these personnel needs.

In some states, this process is already occurring. More training programs are becoming aware of the needs of the young delayed population and are preparing their graduates accordingly. Many university-affiliated programs offer training and practica in needed skills for a variety of professionals. These programs should only increase with the availability of personnel preparation grants as detailed in P.L. 99-457.

Noncertified Professionals in Early Intervention. In many states that have not had mandated early intervention services prior to the passage of P.L. 99-457, it is common to find personnel who are not certified in any area and, in some cases, to find early interventionists who do not hold bachelor degrees. In a recent survey of early intervention providers in Utah (Huntington, 1988), it was found that 23% of the providers had only a high school diploma or associate's degree. Of those providers that had a bachelor's or master's degree, less than 55% had any form of certification or endorsement. In Oregon, a state mandating services prior to P.L. 99-457, it was found that 78% of early intervention teachers surveyed did not hold any form of certification (Teaching Research, 1985). Clearly, training issues for currently employed early intervention personnel will be a concern for many states.

There are three main areas of concern regarding the issue of noncertified personnel currently working in the field if a state implements certification standards for early childhood interventionists: 1) What action should be taken with personnel who are certified in an area other than as an early childhood interventionist? 2) What action should be taken with professional personnel who are not certified in any area but have an advanced degree (bachelor's or master's)? 3) What action can be taken with people who do not have a bachelor's degree (i.e., the paraprofessional)?

Issues number 1 and 2 can be dealt with concurrently. One option is for the state to "grandfather" these people, giving them early intervention certification based solely on the fact that they are currently providing services. This is not accepted as a viable option by experts in early intervention (cf., Bricker and Slentz, in press). "Grandfathering" does not insure that the people employed are appropriately qualified. Having unqualified people provide services would not be fair to the children receiving services and would not be in keeping with the intent of P.L. 99-457. A more viable approach for these professionals is to adopt a competency-based approach to certification (Hutinger, 1983; Woodruf, 1985). The competency-based approach can be used in place of more traditional approaches for these professionals (Woodruff, 1985). Certifying agencies can work with training institutions to develop competencies; usually an "on-the-job" approach. Personnel that meet the competencies would be able to be certified. For personnel that do not meet the competencies, a remedial program can be recommended. This remedial program could consist of university courses, inservice education, and/or supervised experiences that a person implements "on-the-job." After a certain period of time, competencies can be reevaluated. All personnel currently employed that need certification could be allowed a prescribed amount of time to demonstrate competency.

For personnel who do not currently hold a degree, the situation is more difficult. In rural areas, it is frequently difficult to get certified staff, and the people that are working may be the only one willing or able to assume the position. Unfortunately, without a bachelor's degree, it is virtually impossible to receive certification (in some states, a master's degree is required). These personnel would be forced to return to an approved university program to become certified, an option that may be impossible for many.

In most service options that states develop, there will be a need for paraprofessionals. The extent to which paraprofessionals will be utilized will vary depending on a number of factors; including the service setting, whether the community is rural or urban, and financing for services. For example, direct service in rural areas could be provided by paraprofessionals under the supervision of a certified early interventionist. Children integrated into mainstream settings such as Head Start or community child care settings may be provided services by paraprofessionals. Models such as these have already been established (e.g., Rule et al., 1987).

In situations when paraprofessionals may be used, consideration should be given to implementing a program similar to the Child Development Associate (CDA) Credentialing and Training Program (Trickett, 1979). The CDA program has been used extensively by Head Start to provide their staff with appropriate competencies (see Peters and Deiner, 1987). Such a program could be adapted for training early childhood special education personnel.

Preservice Training

Programs. The past sections have described specific skill areas needed by early interventionists. One question raised by this is: What programs, at the preservice level, are preparing personnel to meet these specific skill needs? To help answer this question, a survey of federally funded early intervention personnel preparation programs was conducted.

The majority of personnel preparation programs that focused on early intervention and that offered a terminal degree (i.e., bachelor's, master's, doctorate) were housed in university departments of special education (cf., Bricker and Slentz, in press). The remainder of early intervention terminal degree programs focused on early intervention were housed in university nursing departments. The majority of these programs focused on preparing personnel to work with children from birth through 5 years of age, regardless of where housed. In addition, the skills required by personnel across these two disciplines were very similar.

The following is a list of programs that responded to the survey. Each program is listed by the name of program and program location. A contact person is listed, where available.

A Program to Prepare Early Childhood Special Educators to Teach in the Least Restrictive Environment
Department of Special Education
Utah State University
Logan, UT
Sarah Rule

B-3 Training Project
Wheelock College
Boston, MA
Susan McBride

B-7 Training Project
Wheelock College
Boston, MA
Margot Kaplan-Sanoff

Caring for Special Children
Greater Minneapolis Day Care Association
Minneapolis, MN

Child/Adolescent Nursing Training
School of Nursing
University of Wisconsin
Madison, WI
Karen Pridham

Child Development Assistant Program
Gloucester County College
Deptford Township, NJ
Berminna Solem

Children With Handicaps: Family Centered Nursing Graduate Specialty
School of Nursing
University of Washington
Seattle, WA

Children's Development and Rehabilitation Center
Oregon Health Sciences University
Portland, OR
Abby Rothchild

Children's Hospital of Los Angeles (UAP)
Los Angeles, CA
Don Gobard

Children's Rehabilitation Unit UAF
University of Kansas Medical Center
Kansas City, KA

Clinical Nurse Specialist in Maternal Child Health (child health, neonatal/perinatal, nurse midwifery)
Nell Hodgson School of Nursing
Emory University
Decatur, GA

Clinical Specialist in Pediatric Primary Care
Department of Family Health Care Nursing
School of Nursing
University of California
San Francisco, CA

Department of Child Development
Austin Community College
Austin, TX
Ann Martin

Department of Communications Disorders
Utah State University
Logan, UT

Department of Communications Disorders and Speech Science
University of Colorado
Boulder, CO
Natalie Hedly

Department of Special Education
Murray State University
Murray, KY
Marilyn Hornback

Department of Special Education
University of Idaho
Moscow, ID
Jennifer Olsen

Department of Special Education
University of North Carolina at Chapel Hill
Chapel Hill, NC
Don Bailey

Department of Special Education
University of Wisconsin
Madison, WI
Lisbeth Vincent

Developmental Evaluation Clinic
The Children's Hospital
Boston, MA
Eunice Shishmanian

Early Childhood Handicapped
Department of Special Education
University of Wisconsin
Eau Clair, WI

David Franks
Early Childhood Masters Training
Department of Special Education
University of Maryland
College Park, MD
Paula Beckman

Early Childhood Special Education
Department of Child Development
Iowa State University
Ames, IA

Early Childhood Special Education
Department of Special Education
University of Pittsburg
Pittsburg, PA

Early Childhood Special Education
School of Education
University of Colorado
Denver, CO

Early Childhood Special Education
University of Guam
Guam

Early Childhood Special Education/Infancy Specialization
Department of Special Education
Champaign, IL
Laird Heal

Early Childhood Special Education Personnel Preparation
Department of Special Education
San Francisco State University
San Francisco, CA

Early Childhood Special Education Program
San Francisco State University
San Francisco, CA
Mary Frances Hanline

Early Intervention Program
Center on Human Development
University of Oregon
Eugene, OR
Ruth Kaminski

Facilitating Supportive Interactions Between Parents and High-Risk Infants by Nurses in the Neonatal Intensive Care Nursery
State University College at Buffalo
Buffalo, NY

Facilitator-Specialist Program
Graduate School of Education and Human Development and Department of Pediatrics
University of Rochester
Rochester, NY
C. Chandler

Family Infant Specialist Training Program
Western Carolina Center
Morganton, NC
Scott Snyder

First Start: Care of Handicapped Infants and Toddlers
School of Nursing
University of Colorado
Denver, CO

Graduate Interdisciplinary Option in Infant Intervention
Virginia Institute for Developmental Disabilities
Virginia Commonwealth University
Richmond, VA
Bernadine Clark

Graduate Training in Early Childhood Special Education
Division of Special Education
California State University
Los Angeles, CA
Diane Klein

Handicapped and At-Risk Infant Stimulation
Departments of Special Education and Communication Disorders
University of Nebraska
Lincoln, NE
Cordilia Robinson

Handicapped Services
Department of Child and Family Education
Sinclair Community College
Dayton, OH
Karen Winston

Infancy/Preschool Special Education Specialization
State University College at Buffalo
Buffalo, NY
Judith Bondurant-Utz

Infant Hearing Resources
Portland, OR
Nancy Rushmer

Infant Specialist in Interdisciplinary Studies
Graduate School of Education
Rutgers University
New Brunswick, NJ
Wendy Mathews

Infant Specialist Training
Department of Special Education
University of Maryland
College Park, MD
Paula Beckman

Infant/Toddler Personnel Preparation Program
Center for Early Childhood Learning and Development
East Tennessee State University
Johnson City, TN
Marie Welsch

Inpatient Unit, Nursing Department
Division of Developmental Disabilities
Department of Pediatrics
University of Iowa University Hospital
Iowa City, IA

Interdisciplinary Infant Specialization Program
Georgetown University Child Development Center
Washington, DC

Interdisciplinary Infant Training Program
CDMMRC
University of Washington
Seattle, WA
Susan Harris

Kennedy Institute for Handicapped Children
Baltimore, MD

Mailman Center for Child Development
University of Miami School of Medicine
Miami, FL
D.R. Dickson

Masters Nursing Program
School of Nursing
University of Wisconsin
Madison, WI

Postgraduate Training for Physical Therapists for Newborn and Infant Care
Division of Physical Therapy
Medical School
University of North Carolina at Chapel Hill
Chapel Hill, NC
Irma Wilhelm

Preparation of Early Childhood Special Education Rural Service Providers
University of Washington
Seattle, WA
Tineke Anderson

Preparation of Personnel to Provide Special Education and Related Services to Newborn and Infant Handicapped Children
University of Washington
Seattle, WA

Preparation of Special Educators in Early Childhood Special Education
Department of Special Education
Vanderbilt University
Nashville, TN
Jan Hawley

Preparation of Special Educators to Work With Handicapped and At-Risk Infants and Toddlers
Department of Educational Psychology
University of Connecticut
Storrs, CT

Preparation Program for Parent-Infant Specialists
Department of Education
Gallaudet University
Washington, DC

Preparing Preservice Orientation and Mobility Specialists and Teachers of Visually Impaired to Serve Visually Impaired and Multihandicapped Infants and Their Families
Division of Special Education
California State University
Los Angeles, CA
Rona Pogrund

Program in Pediatric Physical Therapy
Hahnemann University
Philadelphia, PA

Sparks Center for Developmental and Learning Disorders
Birmingham, AL

Specialized Interdisciplinary Project in Early Intervention
Shriver Center
Waltham, MA
Pat Rissmiller

UCLA Neuropsychiatric Institute (UAP)
Los Angeles, CA
Cecily Betz

0-3 Personnel Preparation Project
Western Illinois University
Macomb, IL

For more detailed information on this survey, contact: Mark Innocenti, Early Intervention Research Institute, Developmental Center for Handicapped Persons, Utah State University, Logan, Utah 84322-6580.

Issues regarding what discipline is most appropriate for training early interventionists need to be reconsidered. Bricker and Slentz (in press) discuss the fact that early interventionists in many departments are provided instruction from professionals in many disciplines. Regardless of the academic department in which preservice training for early interventionists occurs, skills needed by early intervention personnel must be, and currently are, focused on the services needed by young children with disabilities and their families. There may be differences in skills that personnel prepared in these different academic departments are taught outside of early intervention related courses, but this should be viewed as an advantage, providing flexibility in the assignment of personnel to various service settings.

State policies should reflect the fact that early intervention personnel are being prepared by different university departments. Provisions must be made to look at the skills and competencies personnel have, rather than where they were trained. This knowledge must influence states when setting personnel standards and certification/endorsement requirements.

Another finding from the survey was the many early intervention personnel preparation programs did not grant degrees and were multidisciplinary in focus. Personnel from other related early intervention disciplines are being trained in these programs. Generally, these programs provided training to people who already held a degree (e.g., bachelor's) in their field, or who were working toward a graduate degree. Training experiences such as these need to be considered when developing state personnel standards for related disciplines that provide early intervention services.

Preservice Planning. P.L. 99-457 does not create the facilities to provide preservice training, but it does provide for assistance to implement such programs. Many people feel that there is no substitute for quality preservice training, that this is where the best training will take place. These grant monies will only be made available to those who have the inclination to apply for such funds, and then the applying institutions must demonstrate that there is a need and a plan by to fill it. It may appear at first that those people not involved with a college or university can have little affect over what occurs at the preservice level, but this is not true. There are steps that individual, and state groups can take to facilitate the preservice process.

One step would be for the state to establish a demonstrated need for personnel to work in the area of early intervention. This can be accomplished in a number of ways. The state can conduct a survey to determine areas of personnel weaknesses in relation to present and future needs. Data attributing the fact that weaknesses exist provides an impetus for attempting to obtain grant monies.

A second step is for states to establish some type of certification requirements for early intervention personnel. In all areas of services for the handicapped, funding has become an issue. For training institutions, the establishment of a new program can be a costly endeavor. New courses will be required, new practica sites developed, and people to provide training are necessary. Without the guarantee that there will be people who will require this new training, the institutions may not want to take the financial risk involved.

A third step is for those who have control over what occurs in early intervention to publicly support the need for early intervention and qualified personnel to provide services. This support needs to come from local providers of service, as well as from State organized committees, such as boards of education, health organizations, and advisory committees that support these groups and the handicapped. Steps such as these will demonstrate State support for early intervention and provide training institutions the optimal conditions for applying for grant monies and establishing new programs.

Curricula. The issue of what specific courses and practica will be required by students in training institutions who are being prepared to provide early intervention services is one that has been repeatedly discussed by experts in the field of early intervention, and some consensus has been reached. The following is a general list of competencies drawn from a variety of sources (e.g., Hutinger, 1983; Zeitlin, Verglas and Windhover, 1982) and research (McCollum, 1987).

Competencies for early childhood special education:

1. Typical child development
   a. All areas

2. Atypical child development
   a. All areas

3. Family involvement
   a. Communication skills
   b. Stages of family growth (normal and delayed)
   c. Strategies for parents to work with children at home
   d. Advocacy and care management by parents
   e. Counseling skills

4. Program planning and implementation
   a. Service delivery models
   b. Least restrictive environment
   c. Instructional assessment
   d. Developing IEPs and IFSPs
   e. Organize learning activities
   f. Plan learning activities
   g. Individual and group learning activities
   h. Analyzing progress data

5. Evaluation and assessment
   a. Program evaluation
   b. Parent satisfaction
   c. Child evaluation
   d. Community collaboration
   e. Testing and measurement

6. Professional development
   a. Interdisciplinary/transdisciplinary skills
   b. Leadership skills
   c. Policy/advocacy
   d. Case management
   e. Transition planning
   f. Interagency cooperation

These competency areas will, at each institution, be translated into specific courses and practicum experiences. Agencies that coordinate certification with training institutions can meet to ensure that desired competencies are covered, assuming that some form of certification exists.

New issues in meeting personnel needs for P.L. 99-457 will be the family orientation and the range of needs that may be identified in the IFSP.

"I am concerned," says one home interventionist who has been working in a birth to three program for many years, "about my own abilities to deal with the scope of the IFSP. I don't want to do marital counseling, I am not trained for that. Will it be expected? We have to be up front about the limits of this component. Alcoholism in parents is a problem for the children I work with, but am I supposed to diagnose that?"

In light of this new emphasis, the need has been expressed by many professionals for coursework in such areas as adult learning and family counseling. There is also a sense that preservice training needs to involve more actual contact with families. "I think," says one parent, "that professionals ought to know something about what a week in the life of a family with a special needs child is like." Internship time in parent-child play groups or with parent-to-parent support groups might be a valuable addition.

Some current professionals, particularly those in university towns, have concerns about the impact of more observation time and more internship time with the families that they serve. "On the one hand," says an administrator, "I don't think my staff is very receptive to the idea of students coming along to observe. It is very hard sometimes on the families to have observers. On the other hand, think of sending out a graduate from our program to a first job without ever having seen a family having problems. That isn't very realistic either. We need some kind of compromise here." A balance will clearly need to be achieved on this issue.

Another issue that requires consideration in developing preservice programs is to what degree programs will be competency-based or traditionally based. Competency-based or performance-based training is training that is based on the learner's ability to demonstrate specific skills that will be required "on-the-job," along with knowledge-based information. Traditional approaches generally stress knowledge-based information (cf., Houston, 1974). Competency-based approaches to training are strongly advocated by those preparing personnel for early intervention (Hutinger, 1983; Linder, 1983). Competency-based education can be obtained in classrooms, practica, or job experiences. The primary requirement is that these experiences require the learner "to write," "to do," or "to describe," rather than "to understand" or "to perceive." Competency-based approaches are appropriate for all intervention involved personnel. State certification authorities need to interact with training institutions to help them focus on competency-based approaches.

Inservice Training Needs

The passage of P.L. 99-457 forces many states into a period of transition while plans are made to incorporate the new law into practice. This transition period is a time when currently employed personnel must prepare for the implementation of early intervention service according to the new plan. For many of these personnel, inservice training may be necessary. Sixty-five percent of the 50 states noted the need for well-trained personnel to work with infants and young children. Most states, that were planning training efforts, proposed short-term inservice programs. This is of concern because according to Campbell, et al., "short-term episodic types of inservice training have, as a whole, been found to be a less effective means for training the longitudinal, field-based training (Campbell, Bellamy and Bishop, 1987).

However, given the time constraints of implementing services to young children and their families in the near future, states may be forced to employ inservice training methods. By linking inservice programs and model demonstration projects, states may be able to improve the quality of the training over that available from random training programs (Campbell, et al., 1987).

Prior to beginning this endeavor, the training needs that must be met should be assessed. An efficient and low cost method to assess these needs on a large scale is through a questionnaire.

The specific nature of the questionnaire will differ depending on the patterns of early intervention service delivery that have been occurring in the state. The questionnaire should, if possible, be completed by all organizations that have been providing early intervention services. The questionnaire should address a number of areas: program demographics including numbers of children served and types of handicaps needed to be included. One section should address current staffing patterns, looking at the disciplines of staff members, types of degree and certification, and years of experience. Another section should attempt to assess the strengths and weaknesses of personnel and in what areas training seems appropriate. The preferences of personnel in regard to receiving training should also be assessed.

These areas do not represent a complete listing of questionnaire topics. If some of this information is already known, then fewer areas may need to be assessed. Conversely, a state may wish to ask questions related to other topics. A questionnaire created by the Early Intervention Research Institute at Utah State University for the State of Utah. Another source for information on this topic is the chapter on Staff Development in **Early Childhood Special Education: Program Development and Administration** (Linder, 1983).

Once the questionnaire has been completed, it can be used to determine inservice needs. As discussed earlier, an option for meeting these needs is through a combination of courses and "on-the-job" evaluation. Inservice training can be competency-based. Prescriptive programs based on the "on-the-job" evaluations can be implemented such that personnel can become competent while working in a meaningful setting. Other inservice options are possible, but the combination of class experience and "on-the-job" preparation appears to be one where service providers, children, and the system can benefit.

Personnel development at the local level differs slightly from that conducted on a larger scale. The main difference is that the personnel involved can and should have a larger input regarding what occurs. Inservice projects have found that greater involvement of personnel in developing the inservice and in planning evaluation activities results in inservice efforts being better received and more effective. A model of personnel development has been developed by Linder (1983), with the following main features:

1. The knowledge, attitudes, and skills needed by staff are identified.
2. Staff members are assessed to determine their strengths and weaknesses in relation to identified standards.
3. Prescriptions for growth and development are written to improve areas of weaknesses.
4. Learning alternatives that will enable staff to acquire requisite competencies are identified.
5. The process is evaluated to determine whether objectives have been met and what directions future training will take (pp. 187-188).

This model can serve as a personnel development model for a variety of settings and development purposes. The model needs to be put in the context of the goals and objectives of the personnel development needs (i.e., increasing knowledge of a particular area, demonstrating skill competencies.

This model can serve a number of purposes. It can be used for professional personnel, paraprofessionals, and parents. Depending on the group or individual being trained and the goals of training, the conduct of each step will vary. For example, when you develop prescriptive plans you should consider the level of knowledge needed; whether it be to develop an awareness of an area to help the individual become an expert. Decisions such as these need to be made at each level.

Cooperation Between the State and Training Institutions

Too often in the past, training institutions have established programs that do not accurately reflect the service patterns established by the state. This can have advantages and disadvantages. Students may learn more than they need to know to get along in the state system, but conversely, they may have skills that do not allow them to readily adapt to the service system in place. The climate established by P.L. 99-457 is one in which cooperation between states and training institutions could flourish. To implement this, states and training institutions can work together to meet future personnel needs as well as address present personnel needs in the form of inservice and other local training activities. By working together, the needs of each participant can be more adequately met, and the end result will be a benefit to our young children who are handicapped.

SUMMARY: What is Realistic?

In setting up personnel standards and training requirements, it is everyone's idea that we should have the best for children with special needs and their families. But what can we really ask for? While the task is complex and demanding, the financial rewards are still not very great, in the context of our societal devaluing of childcare as a whole. Says one agency administrator, "I have seen the kinds of expectations that people are asking of early intervention workers. I think if you get people with all that knowledge and training, you are **not** going to find them working with families in community based programs. You are going to find them in university settings where their status and income are higher."

The frontline workers traditionally have been paraprofessionals and basic professionals, not specialists. If we really want the highest caliber of professional working in this area, there must be long range public awareness efforts, and within-agency efforts, to boost morale and provide rewards.

"We need some kind of career ladder for personnel who work well with families," one administrator says. "We have to say, You're doing your job when you're working with families and we need to make the community understand that. We need to indicate at every level that this is a valued activity. Without value, the system won't work."

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CHAPTER 9

What kind of management and monitoring is needed to see that the goals of early intervention are accomplished?

Early intervention takes place in the interaction between children with special needs and their families and professionals and paraprofessionals who offer support resources for them. Collaboration between parents and professionals may take place at a very vulnerable period in a family's history. As intimate as that collaboration can be, it is part of a public service system structured and strengthened through P.L. 99-457. Services need to be managed and that management, that administration, becomes less intimate as it broadens.

Closely tied to administration and monitoring functions is the identification of the lead agencies and the establishment of interagency coordinating councils called for in the law. The roles of these state-level bodies in carrying out the planning and implementation of the law will clearly vary. They will all, however, have the opportunity to set the tone for a system that will be truly family-centered, with both interdisciplinary and interagency coordination in keeping with the spirit of the law. In this section we would like to explore the importance of that participation along with some key issues that will face these bodies in the planning process: administrative procedures, interagency agreements, due process and decisions related to funding priorities.

Lead Agencies and Interagency Coordinating Councils

Although education, health, and social service agencies must all participate in providing early intervention services to handicapped children, certain agencies are designated as having, "lead responsibility." For 3 to 5-year-old children, the state education agency serves this role. For 0 to 2-year-old children, states must choose who will be the lead agency. The importance of interagency coordination is underscored by which agencies have been selected by states as the lead agency for 0 to 2-year-old children as show in Table 9.1.

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Table 9.1

Frequency with Which Different States Have Designated Various Agencies as the "Lead Agency" for Early Intervention Programs Funded Under P.L. 99-457

Education	Health	Health and Social Services	Developmental Disabilities	Human Resources	Other Agency	Interagency Coordin. Council
Alabama Colorado Connecticut Delaware Florida Illinois Iowa Louisiana Michigan Minnesota Missouri Nebraska New Hampshire New Jersey Oklahoma S. Dakota Tennessee Vermont	Hawaii Kansas Massachusetts Mississippi New Mexico New York Ohio S. Carolina Utah W. Virginia	Alaska Washington Wisconsin Wyoming	Arizona California Idaho Montana Oregon	Arkansas Dist. of Columbia Georgia Kentucky Nevada N. Carolina N. Dakota Pennsylvania	Indiana Maryland Virginia	Maine Rhode Island Texas
TOTAL # OF STATES: 18	10	4	5	8	3	3

State education agencies have been selected as the lead agency in 18 states; 10 states have selected the state departments of health; 10 states have selected another agency (e.g., mental health, human services, developmental disabilities); and 3 states have selected their Interagency Coordinating Council. The wide range of departments selected as lead agencies underscored the "ownership" felt by many different agencies for early intervention, and emphasizes the potential benefits of interagency collaboration.

The Interagency Coordinating Councils (ICCs) are established to advise and assist the lead agency in its responsibility and in promoting the interagency agreements. The Councils are to be composed of 15 members, including at least 3 parents of children with disabilities under six years of age, 3 providers of early intervention services, 1 legislator and 1 person involved in personnel preparation.

Participation in Decision-Making

There will be many decisions to be made related to the implementation of the 14 minimum components of P.L. 99-457, Part H. Interdisciplinary efforts are the goal at the point of service delivery. Interdisciplinary consensus, through the IFSP, is in a sense the centerpiece of the legislation. But interdisciplinary and interagency decision-making is also a special administrative feature of this legislation. While there is a lead agency in carrying out the process, there is not one single agency in charge, nor is one agency receiving the funding or being expected to pay for services. P.L. 99-457 is intended to be a collaborative effort, from the point where services touch the family up through the various levels of administration.

In the model presented in Chapter 1, a place is made for significant input related to each of the 14 components by a wide variety of people, from families and grass roots practitioners, to federal agency administrators. Who is going to be affected by each decision and who has the experience and wisdom to contribute to making good decisions on particular areas? A process must be structured for this kind of involvement.

One mother of a high-risk infant who serves on the interagency coordinating council in her state sees a need for a very pragmatic assessment of who can be useful on that body. "As a parent, I know that I've talked more about insurance in the last three years than I ever dreamed possible. It dominates our lives, it determines sometimes where we can live and what kind of job changes we can make. And insurance will be a big topic in this legislation--what private carriers will pick up what. Now why isn't the insurance commissioner for the state or

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someone from that office on our board? That would be really useful."

Another parent serving on the ICCs feels it is important that parent decision-making be taken seriously enough to make it feasible for parents to participate. "One thing that is happening in our council is that there are three parents on the council. And for all of us it's very difficult to make the meetings because of child care or medical complications. Even planning two months ahead maybe I can't make it because my child is going in the hospital. I don't make excuses for not being there. That can't be helped. I think you need to **hire** parents if you want them to participate at this level. If I go to these meetings and make my family pay for my volunteering, it's the wrong message. I don't work for an agency and I don't have compensation for time and money. I think a lot of parents groups and a lot of agencies need to know that you can't run on volunteer time and expect to get good quality participation from people."

In addition to parents, direct care practitioners also feel the effects of administrative decisions, and have important experience to be brought in on the policy and planning stages.

"I am very concerned about the possible complexity and time involved in getting a child and family into the system. If agencies have to sit down to arrange this together, it could take forever. I've seen how long it takes to set up all those meetings and everyone has to change their schedules around. I have a lot of home visits, and my being there for families on a regular basis, every Monday at 2 P.M. or whatever, is very important for them. It could cause some serious problems if there isn't a way to do it efficiently. I hope the law works so that only in some cases interagency stuff has to be done in a physical sense, and others can be done by paper work."

Issues Related to the Development of Administrative Procedures

There are many issues and problems that can occur between the passage of a federal law that mandates a new social program and the distribution of written procedures for implementation of that program within a state. The federal government may prefer to give states considerable leeway in developing state plans and concomitant legislation. Therefore, as with P.L. 99-457, the federal administrative agency may either delay the publication of federal regulations governing the program and/or promulgate regulations that are extremely broad and non-specific. The lack of rigid direction from the federal administrative agency provides each state with the opportunity to be creative and to establish state plans that are compatible with existing service delivery systems and state government structures. However, while maximizing state autonomy and ensuring the development of individualized state plans and program policies, ambiguous federal rules and regulations can create fields of conflict between service providers and state administrators or between consumer advocacy groups and state administrators.

Conflicting opinions regarding the intent of the federal law can delay the writing of the state plan and the development of procedures for implementing that plan. Unresolved conflict can lead to expensive lawsuits between individuals, provider associations, or consumer groups and state government agencies. Therefore, it would seem that the broader the federal regulations and guidelines governing the program, the more important it is to involve representatives from the various public and provider interest groups in the design and development of the proposed state plan. To the extent that the Interagency Coordinating Council is broadly representative of the various provider and consumer groups, the Council should be able to prevent critical conflicts from emerging or negotiate conflict resolutions in a timely manner.

ICC members and state administrators will face the same dilemma as federal administrators when they write the state plan and procedures for implementation of a state program that is equitable and effective. Procedures that are too rigid may preclude children and their families from receiving the needed services. Likewise, procedures that are flexible and can be broadly interpreted may result in the inequitable distribution of services and more opportunity for disagreements that may be resolved through appeals.

Interagency Coordination

One of the most difficult aspects of interagency coordination will be deciding which agencies will be responsible for which aspects of the program. The lead responsibility for both Part H and Section 619 is established by law, but the mechanism for accomplishing effective cooperation is outlined only in broad terms. For example, under Section 619, the State Education Agency is charged with the responsibility to:

> "...set forth policies and procedures for developing and implementing interagency agreements between the State Educational Agency and other appropriate state and local agencies to, (A) define the financial

> responsibility of each agency for providing handicapped children and youth with fee appropriate education, (B) resolve interagency disputes, including procedures under which local educational agencies may initiate proceedings under the agreement in order to secure reimbursement from other agencies or otherwise implement the provisions of the agreement."

Although this section of the law makes it clear that interagency cooperation and participation are essential, it does not make it clear how that will happen. Saying that policies and procedures must be developed to, "resolve interagency disputes" and finding the mechanisms to do it are very different. We have learned a great deal and interagency cooperation has improved dramatically as a result of P.L. 94-142. An important part of implementing P.L. 99-457 will be to build on what has been learned and to develop models and mechanisms by which such cooperation can happen.

Interagency coordination is an area where the federal government needs to continue to provide leadership and support. Several federal agencies are already making efforts in this direction. A federal Interagency Coordinating Council parallel to the state Councils has already been organized and is functioning. A joint effort of the Bureau of Maternal and Child Health and the Office of Special Education and Rehabilitation Programs has organized a project to examine how Medicaid and other third-party payments can be used to support early intervention programs.

Interagency Agreements

There are three types of interagency agreements that may be required under P.L. 99-457, depending upon the structure of the service program within each state. The first is an interagency agreement between state government agencies responsible for administration of the program. The second would be agreements between the lead administrative agency and the service providers, and the third would be agreements between health service providers and local education agencies or among health services providers at the community level. Most interagency agreements will:

1) State the purpose of the agreement;
2) Identify the parties covered by the agreement;
3) State the duration of the agreement;
4) Describe the role and responsibility of the participating agencies;
5) Identify the population to be served by participating agencies;

6) State the criteria that will be used to determine the amount of reimbursement that will be provided for services; and
7) Establish procedures for monitoring and evaluating outcomes.

Interagency Agreements Among State Government Agencies. This type of agreement is sometimes referred to as a "Memorandum of Understanding." The purpose of this agreement is to identify how the state will meet the requirements of the federal law. Basically, it should identify agency responsibilities and how the responsibilities are to be carried out. It is a document designed to guide administrators in the planning and implementation of the program. An exemplary interagency agreement has been developed by the State of Minnesota. Agencies participating in this agreement include the Minnesota Department of Education, the Department of Health, and the Department of Human Services. The purpose of this agreement is to provide direction to the State Interagency Early Childhood Intervention Steering Committee, that is responsible for 1) dissemination of information to departmental staff regarding interagency collaboration and programs; 2) consultation to the State Interagency Council in determining priorities for service planning, development, implementation and evaluation; 3) dissemination of informational materials to school districts and local health and human service agencies; and 4) coordination of technical assistance being provided on early intervention and inservice activities. While each state will need to consider its own unique situation, this Interagency Agreement provides an example of one that is clearly written, brief and practical.

Interagency Agreements Between State Agencies and Service Providers. This type of agreement can be difficult to secure. The best resource for guidance in this area may be the state agency that administers the Medical Assistance Program. Under Title XIX of the Social Security Act, contracts must be established between the state administering agency and the local service providers to ensure the effective delivery of medically necessary services. For example, Wisconsin has contracts with over 30,000 health care providers, including physicians, dentists, occupational therapists, physical therapists, psychotherapists, social workers, home health agencies, rehabilitation agencies, personal care workers, and others who provide health/medical services to people on medical assistance. The contract is identical for all types of providers, except for the reimbursement methodologies, and it is quite brief. Basically the contract holds providers responsible for the procedures and policies as they are stated in Wisconsin regulations. Hence, the contract negotiations can focus on reimbursement criteria, which are negotiated among professional associations by state agency staff. Because Wisconsin law requires all program to promulgate administrative rules through the legislature, any changes in program policies and procedures must go through the legislative process and be included in Wisconsin's administrative code. This has the advantage of making program policies and procedures less susceptible to frequent administrative changes and easily accessible to the general public. It also minimizes the number of formal appeals, as state agency staff familiar with the Medical Assistance administrative code can resolve disagreements through direct consultation with program beneficiaries and/or service provider(s). While P.L. 99-457 does not mandate contracts between the state administrating agency and health care providers, ICCs may decide this is an important component for monitoring the quality and effectiveness of services. In that instance, states may be able to document that providers meet the required licensure or certification criteria for providing services by piggy-backing on the Medical Assistance certification and licensure requirements, and thereby save time and money.

Interagency Agreements at the Local Community Level. Interagency agreements among health providers at the local level or between health providers and local education agencies again may take the form of letters or "memoranda of understanding." The need for this type of agreement will, to some extent, depend upon the amount of documentation the state will require to substantiate that agencies are working together cooperatively. Conceivably, agency staff and providers within local communities will not be motivated to work together collaboratively simply because a letter of agreement has been signed by their administrators. However, such agreements may serve as a guide for agency staff as they make decisions regarding the provision of services and the management of services to children and their families within their community.

Consumer Participation. Regardless of which type of interagency agreements are developed by each state, it is important to remember that these agreements are the foundation for cooperation and collaboration amongst agencies in the planning and implementation of program procedures. These agreements also will have a direct effect on the quality and availability of services for children and their families. Therefore, it is critical for consumers, or representatives of consumer groups, to participate in the negotiations governing the interagency agreements. This is probably most important at the level of interagency agreements between the state administering agency and health care providers, and among health, education and social service agencies at the local level. Such agreements will affect the quality and quantity of services regardless of the efficiency with which the program procedures are written. The recent expansion of health maintenance organizations throughout this country has increased the awareness of consumers regarding issues of access, availability, and quality of health care services. Many consumer groups in the field of developmental disabilities have expressed concern regarding these service issues and have become more alert to contractual agreements that affect their care. Including consumer representatives in the contract negotiations, as well as the procedural discussions would seem to be an important quality assurance step.

The Concurrent Service Delivery Model. The Concurrent Service Delivery Model was developed at The University of Washington, Seattle, to address the problem of coordinating services from multiple agencies (Tazioli et al., 1987). The Concurrent Services Delivery Model project staff began their efforts by interviews with multiple providers of human services to obtain information regarding the types of problems frequently encountered when trying to provide programs across agencies. The outcome of their efforts is a manual which addresses specific strategies to approach creative problem solving and collaborative planning. The strategies are designed to "ensure that interactions between agencies become efficient and comfortable for all participants, and that interagency cooperation becomes more beneficial and productive for professionals, parents, and children alike." Successful completion of the strategies require parent involvement and administrative support.

The Concurrent Services Delivery Model is adaptable and can be implemented in a variety of ways. The guidebook contains a "Concurrent Services Troubleshooting Guide" which helps to identify strategies by matching concurrent service problems with specific strategies. The strategies could also be used in a systematic fashion, implementing each strategy as it is worked through. During preliminary meetings, the players, be they state or local level planners must reach mutual agreement regarding the strategies to implement.

The specific topics covered in the Guidelines cover five issue areas: Identification and Awareness, Communicating among Service Providers, Individualized Planning, Communication with Parents, and Evaluation of Concurrent Services Activities. For each issue service providers are given "recipes" to enhance the quality of their collaboration.

The use of formal procedures, or guidelines can provide a framework for service providers to develop concurrent services which meet the needs of infants and toddlers and their families which are successful and responsible to family needs and strengths. The precedent for this kind of planning and cooperation must come from the lead agency and the Interagency Coordinating Council.

Accountability and Due Process

Early intervention takes place in the interactions between families and professionals, and the plan for that interaction is in the IFSP. What happens when parents feel the IFSP does not reflect their family's real needs, or when the services outlined are not delivered in a timely manner? There is an ample legacy of court cases under P.L. 94-142 to serve as examples. Some parents receiving services in those states with 0-2 programs have already had experiences with due process for this age group.

Since IFSPs will represent plans jointly developed by family members and professionals to specify both strengths and needs in the child and family, a thorough system for monitoring the quality and appropriateness of IFSPs would be a prime "due process" preventive effort. Questions involved in this monitoring would include:

1. What will the collaborative process of developing the IFSP be like? How will the decisions of parents be supported in this process? How will the pitfalls of the IEP meeting be avoided?

2. How will IFSPs be monitored or approved? What administrative guidelines need to be established? Will there be one standard line of authority, or will it vary individually, or by region?

3. How will timelines for implementation of IFSPs be generated? Will they be consistent across each state? How long will families be required to wait to receive services after the initial referral is made?

4. How will due process procedures be incorporated into the development and implementation of the IFSP?

5. What system of evaluating the effectiveness of each IFSP will be established? How should the evaluation system be included in the process of generating the IFSP?

6. How will the IFSP interface with other mandated family service plans, such as those required by medical assistance programs?

Because case management is such a broad and varied process with the needs of every infant, child and family being different, it clearly presents a major evaluation challenge. The outcomes of case management will likely be difficult to identify and measure with any certainty. Yet a pragmatic and fiscal review process must be built into the system if there is to be any assurance that the infants, young children and families are getting appropriate assistance. Questions that should be considered to look at the accountability of case management include the following:

1. Are all possible resources being considered to meet the needs of the infant or child and family as specified in the IFSP?

2. Has there been duplication of referral efforts or service provision or have various agencies been working at cross-purposes?

3. Have family members and service providers been aware of who was doing what, where, when and why?

4. Has the family been satisfied that their needs have been adequately met in a way that encouraged their participation?

In order to evaluate the effectiveness or accountability of the case management being done, it will be necessary to determine who should embark on evaluation efforts, the case managers themselves or outside persons hired specifically for the task. It will also be necessary to consider the formats for gathering data from the families. Written questionnaires, telephone surveys and face-to-face surveys each have their own advantages and disadvantages. The language spoken by the families and the question of literacy need to be addressed when developing the evaluation process.

Due Process. Mandatory and evaluation efforts cannot, of course, take care of all problems in the relationship between families and the service system, and due process can be very helpful. "In mediation, there is a third party to give credence to our concerns," says one parent. "I hate to say it, but that's when I've felt the best decision-making has taken place, where people are really listening to each other. I don't want it to be that way, but that's the way it is."

Due process is the means by which the rights of people, established by a federal or state law, are guaranteed and protected. Generally due process is assured through administrative rules and regulations designed to protect the rights of program beneficiaries and to safeguard beneficiaries from improper or inappropriate rules and written procedures for implementing any new state program is a complex task.

After a law such as P.L. 99-457 has been passed by Congress and signed by the President, federal administrators will write and distribute the **federal regulations** that govern the implementation of the new law. These federal regulations are used by state administrators to guide the development of a **state plan** for implementation and management of the program established by federal statute. The state plan is then submitted for approval to the federal agency responsible for administration of the new program. In most instances, it is necessary to write state **administrative rules and regulations** that must be approved by the state legislature. These administrative rules and regulations provide state programs administrators with the authority needed to direct and manage the new program, and/or protect the rights of the general public and the program beneficiaries. After the state plan has been approved and the appropriate state legislation passed, the **administrative procedures** to be followed throughout the state are written and distributed. In the ideal, administrative procedures provide specific guidelines for carrying out the intent of the federal law--in this case P.L. 99-457.

This, then, is the general process that is followed to protect and preserve the social welfare or well-being of the general public and to uphold the benefits and rights mandated by federal statute for specific individuals. Simply put, due process is assured through the establishment of administrative rules and procedures to guarantee that the proper people receive the proper services according to the intent of the federal law. When these administrative procedures are ineffective, due process frequently is determined through the courts and case law.

Conflict Resolution Through An Appeal Process. When a program beneficiary believes that the state's administrative procedures have not been followed properly, he or she has the right to file and appeal under due process. The main function of the appeal process is to provide a forum for conflict resolution between program administrators and the beneficiaries of the program. During this process, both the beneficiary and an administrator of the program may present their views regarding the disagreement. These viewpoints generally are presented to independent judges, who may be consumers, service providers, or government employees hired to decide appeals.

It is important to remember that appeals are based solely upon the improper and incorrect application of administrative procedures and not upon issues related to the quality or effectiveness of services provided. The appeal process is not intended to protect beneficiaries from poor quality or ineffective diagnosis, evaluation, treatment or other service activities. Generally, it is assumed that the public will be protected from poor quality services through the licensure and credentialing of service providers. In other words, it is a social belief that service providers who have been properly trained and have obtained appropriate certification or licensure will in fact provide adequate and appropriate diagnostic, evaluative and treatment services. People who think they have been treated poorly or that treatment has resulted in increased health problems may choose another service provider or, in the extreme, file a malpractice suit.

Appeal procedures are expensive. Time and money are required to gather documentation, to hear an appeal and, if necessary, to correct procedural errors. In order to avoid unnecessary appeals, it is critical that administrative rules and procedures be clearly written and widely distributed to program administrators, providers and consumers. The appeal process is established to monitor the implementation of those procedures and not to make judgements regarding their validity. Questions or disagreements about the appropriateness of specific procedures, or discrepancies between the procedures and the intent of the federal law, are handled frequently through the courts.

Due Process Issues in P.L. 99-457. One way of evaluating the need for specific procedural safeguards to ensure due process under P.L. 99-457 is to examine some of the critical issues that have resulted from implementation of P.L. 94-142. One important issue is that of least restrictive environment. The question of what "least restrictive environment" has been highly debated. For example, children who require respirator equipment to sustain life are sometimes considered too medically fragile to attend public school. There may be concern among teachers and staff that they will be held responsible for the medical care and treatment of the child within the classroom. School administrators may not have the financial resources under P.L. 94-142 to provide attendant medical care within the classroom. Parents and the child, however, may insist upon classroom attendance so that the child may develop social competencies and relationships in addition to basic educational knowledge. Under P.L. 99-457, the issue of least restrictive environment may become even more muddled. For example, suppose there is a one-year old child living with his/her natural parents on the family farm. Is the least restrictive environment one that permits that child to receive services within their home or one that requires the child to be transported daily to the city school where services are made available? These will not be easy questions to answer and the writing of procedures to ensure due process will be difficult.

Another important due process issue will be that of the child's service needs and rights versus the family's need for the right to privacy. The Individualized Family Service Plan (IFSP), which is mandated by P.L. 99-457 should outline the medical, social and educational needs of the child and the family. Hence, as discussed earlier, P.L. 99-457 mandates that the plans for services include the needs of the family as they relate to the needs of the child. It is entirely conceivable, however, that some families will resent any intrusion from professionals regarding suggestions for their continuing education or perhaps treatment. For example, a parent is alcohol dependent but unwilling to admit to the problem and its affect on the child's care. It is unlikely that this parent will be receptive to any suggestions for including alcohol treatment in the IFSP. Procedural safeguards designed to protect the child's rights and guarantee the child appropriate services may conflict with the parents right to deny services or the family's right to refuse to participate in the IFSP process.

Appeal Procedures under P.L. 99-457. In addition to the due process issues that will be provided for within the administrative procedures, there is a need to examine the actual appeal process. Again, it is helpful to make some comparisons with P.L. 94-142. When such a comparison is made, many similarities emerge, such as the opportunity of parents to examine records related to assessment, written notice of parents if a change in placement for the child is processed, and so forth. There are, however, a number of differences, such as:

1. Under the procedural safeguards for the 0-2 population, there is no mention of where one should go to make a request for a hearing. In P.L. 94-142, the request is made to a state or local education agency. States may want to consider broadening the points of entry into the appeal process by including other agencies in departments of health or social services that are serving the children and families provided for under P.L. 99-457.

2. Under P.L. 94-142, there is a provision for having a hearing by a hearing officer in the schools, appealing to the state education agency, and going to court. However, the 0-2 regulation does not necessarily require that you have a "hearing." Instead, there is just the requirement that an "impartial individual" consider the situation and come to a written decision. Those states using a department of health or social services to administer the program may want to review the appeal procedures established for their

state Medical Assistance program or another of the social service programs, such as the Community Service Program. It is conceivable that there are several existing appeal programs within the state that could be used as a structure for P.L. 99-457 appeals:

3. Under P.L. 94-142, parents who disagree with the evaluation provided by the school can request an independent evaluation. The cost of the independent evaluation must be paid by the school district, unless the district asks for a due process hearing on the need for a second evaluation. There is no mention of second opinion evaluations under P.L. 99-457. The importance of this difference may depend upon the extent to which families are permitted to select the professional or professionals that will do the initial evaluation. It may be that the more families are directly involved in the initial assessments, including selection of the people or agency doing the evaluation, the less need there will be for second opinions.

4. Under P.L. 99-457, there is little or no mention of the following issues regarding appeal procedures a) the opportunity for parents to have someone with them during the hearing; b) rules governing cross examination; c) mandatory attendance of witnesses at the hearing; d) whether the hearing should be open to the public; e) procedures for surrogate parents, including pay to participate in the hearing; f) the parents right to legal counsel; and g) the rights of the child during the hearing.

Resources Available Within Each State. The issues surrounding due process are complex. However, each state has some valuable resources available to assist with the complexities. One important resource will be state education agency staff and administrators of local education agencies who have a great deal of knowledge of due process and appeal hearings through their experiences with P.L. 94-142. A second resource regarding the protection of consumer rights and responsibilities as they relate to the rights and responsibilities of medical and health care service providers is the state's department or division of health that administers the state's Medical Assistance program under Title XIX of the Social Security Act. A third resource would be the state University Affiliated Program which may provide second assessments and have extensive experience with due process issues under P.L. 94-142. A fourth resource is the state's Protection and Advocacy Agency for people with developmental disabilities.

Financing: Funding a Balance

Funding decisions will be an important sign of administrative vision, and to the creative collaboration between families and direct care professionals. The "ideal" mix of how states spend their money will vary from state to state, but decisions should include spending at least some money on program planning and development; personnel preparation; and research and evaluation; in addition to the money spent on direct services. Given the fact that the amount of money available to provide early intervention will probably not be sufficient to do all that they would like to do, there will be a temptation to put all the money into direct services.

Planning and Program Development. Although a handful of states have reasonably well-developed statewide systems of early intervention, most do not. One of the challenges associated with the implementation of P.L. 99-457 is that most states will have to develop completely new programs. The development of such programs will require time and money, and congressional planners wisely recognized that substantial portion of money through FY90 would be needed for program planning. As programs are developed, it is important that administrators learn from the past experiences of successful states.

How should the states and trust territories begin to develop a framework for comprehensive service delivery planning? The task before the states can appear overwhelming. A number of approaches can be adapted from states which have already develop, or are in the planning stages of coordinated, comprehensive service delivery models. Both Massachusetts and Oregon have done important planning efforts that are relevant.

Massachusetts has provided services for at-risk and developmentally disabled infants and toddlers and their families for more than a decade. Services are provided to children who are at risk for poor developmental outcomes due to established, biological, or environmental risk factors. Services to approximately 6,000 children are coordinated through a single agency. Prior to 1983 however, intervention services were provided by more than 100 local programs under the jurisdiction of seven separate state agencies. In 1980 a study known as the Massachusetts Early Intervention Study was conducted, and documented that responsibility for early intervention services was fragmented, with too little administrative leadership or support, and that fiscal and policy direction were lacking. The study proposed more than a dozen recommendations to encourage policy makers to create a unified, responsive system of service delivery to disabled and at risk infants and toddlers (Meisels, 1980, and Meisels et al., 1985).

The process of self study was extremely successful. Within two years after the publication of the report a single state agency had been designated as the provider of early intervention services, and a mandate to ensure services to all eligible children was accomplished shortly thereafter.

Self study of a state's current service delivery system should be the first step in the development of a comprehensive state wide service delivery model. An objective assessment of who currently provides services, what eligibility criteria are used, how the service is paid for, and how the families involved should be conducted with all current providers for service in a state. Barriers to the provision of comprehensive services can be identified through the process of self study. This activity should be the foundation for building the statewide service delivery model.

Oregon passed a mandate to provide services to developmentally disabled infants and toddlers in 1983. Early intervention services provided to infants and toddlers address each child's developmental deficits in sensory, communication, self help and socialization areas. Parenting training, classroom instruction, and transportation services are supplemented by physical, occupational or speech and language therapy. The Oregon legislature directed the Mental Health Division and Department of Education to develop administrative rules to guide the implementation of the new mandate in local communities. Each local community was directed to develop a local Early Intervention Advisory Group to develop a comprehensive written implementation plan (Moore and Towes, 1985).

The Oregon State Plan Grant accepted the challenge of facilitating the writing of local county plans in 1984, as part of the two year grant. The product of their efforts is the **Early Intervention Advisory Group Workbook**. The workbook was designed to help communities translate the intentions and requirements of the new law into comprehensive local plans. Procedures in the workbook assist local planners in collaborative efforts to collect and summarize information for community needs assessment. The workbook assist local communities in designing strategies to conduct local evaluations or programs and plans, make revisions as necessary, and use this information to develop proposals for funding from additional sources. Most important, the formation of local early intervention advisory groups promotes community ownership of the families and children to be served. The workbook provides the community with a vision of a final product of their efforts--a written comprehensive plan and a process for achieving the desired outcome. The formation of local community early intervention advisory groups is an exemplary practice which can be easily replicated in other communities. A systematic approach to community service planning can assist in developing the needed linkages between the State Interagency Councils and the local communities.

The process of self study exemplified in the Massachusetts and Oregon examples can clarify the major issues the Lead Agency, and the ICC must face in the planning process. These issues affect all components of the system, childfind, monitoring and tracking, preventive intervention, and early intervention.

Personnel Preparation. As early intervention programs expand, substantially more qualified personnel will be needed to provide services. If early intervention is to be successfully implemented, people will need to be recruited from the health professions, education, and other human service areas. Both professionals and paraprofessionals have an important role to play and states must decide how to recruit, train, certify and retain the people who will provide early intervention services.

Adequately financing these efforts is extremely important. Furthermore, decisions made about personnel preparation, recruitment and retention have important implications for the financing of early intervention programs. For example, if a State Education Agency decides that all personnel involved in delivering early intervention services to 3 to 5-year-olds must be certified teachers, the cost of providing those services may be very different from another state which makes extensive use of paraprofessionals who are supervised by certified teachers. Despite the acknowledged personnel shortages, few states spent first year Part H monies on personnel preparation issues.

Research and Evaluation. We have argued earlier for the need to systematically investigate which types of services are best for which children. Because early intervention is a relatively young field, we still know very little about the relative cost-effectiveness of different program models. Although it is not difficult to find advocates who will argue vehemently that one methods is better than another, it would be unfortunate and potentially damaging if we allowed the enthusiasm, persistence, or proximity of a particular advocate to be used instead of solid data from research and evaluation studies. Although the federal government will need to take a leadership role in providing such information, state administrators can also contribute to the resolution of such issues in the way that programs are planned and implemented. Providing opportunities for systematic variation, and objectively collecting data about the costs and effects of such variations will do much to improve the quality of early intervention services. Conducting such research and evaluation subtracts from the amount of money available to provide direct services in the short term. But, in the long term, such information will result in more effective services being available for children and their families.

SUMMARY

Putting all the pieces together to provide services and resources to every infant and toddler with special needs will be a complex administrative effort. In the process of working with the pieces, it will also be the job of state level administrators to keep the big picture in mind. The implementation process will be made up of infinite numbers of small steps and someone needs to remind everyone else what the journey is all about.

It will be useful to use the quality of collaboration as a yardstick for everyday small steps in the implementation process. As many practitioners and program administrators will attest, family-centered services and true parent-professional collaboration can be very inconvenient concepts. They can be more time-consuming and less orderly than the application of services by a professional to a child. But experience has clearly shown that these concepts work for the child.

For the same reason, the spirit of collaboration must be kept vital in the administration of the state-wide system called for in the legislation. The meaningful involvement in planning by all of those who will be living by the law will be the key to making the system work.

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Interviews with legal staff at Wisconsin Protection and Advocacy Agency were used to develop much of the material on due process.